

Guidance on the management of fibromyalgia for the multidisciplinary team

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Introduction

Fibromyalgia is a painful, non-articular condition predominantly involving muscles; it is the most common cause of chronic, widespread musculoskeletal pain. It is typically associated with persistent fatigue, non-refreshing sleep and generalised stiffness (Table 1).¹

Fibromyalgia affects about 2% of the UK population² with females outnumbering males in a ratio of 9:1. The most common age group affected is between 45–60, though it can occur at any age, even in children. There is no distinction between ethnic or social groups.

The onset of fibromyalgia can be sudden or gradual, traumatic or non-traumatic. Fibromyalgia can also co-exist with other distinct clinical disorders.³

Prognosis can depend on treatment availability and approach, and the individual's willingness to adopt a self-management outlook. In 1998, Turk et al demonstrated that an interdisciplinary approach exploring concepts of

- Medication utilisation
- Activity scheduling
- Graded exercise
- Cognitive behavioural therapy (CBT)

to be the optimal intervention for individuals with fibromyalgia.⁴

Diagnosis

Fibromyalgia is not simply a diagnosis of exclusion, it is a distinctive syndrome, which can be diagnosed with clinical precision.¹ The diagnostic criteria are based on the American College of Rheumatology definition produced in 1990⁵ (see Table 2). These criteria are widely accepted in the UK and there is growing recognition of fibromyalgia as a distinct subgroup of chronic pain sufferers.⁶

On assessment it is important to take a careful history and to acknowledge the individual's experience and description of pain. Patients with fibromyalgia do not look ill and do not appear clinically weak.⁷ Apart from restriction of movement due to pain and the presence of the multiple tender points, physical examination tends to be unremarkable. Blood tests, x-rays and scans will typically yield a negative result.

Before any intervention is considered, other pathological processes that can cause chronic pain and/or fatigue need to be excluded. Waddell et al, in 1992, first used the descriptive term “red flags”, in the context of back pain, as indicators of potentially serious pathology.⁸

For fibromyalgia, “red flags” indicating other potential pathology could include:

- Involvement of the joints
- Systemic malaise, especially with weight loss
- Evidence of thyroid dysfunction

New presenting symptoms will need to be considered and possibly investigated as they arise. Appropriate referral onto other healthcare professionals will need to be determined at this stage (e.g. a Rheumatologist).

Main Symptoms

- Widespread muscular pain
- Generalised stiffness
- Persistent fatigue
- Non-refreshing sleep

Main Sign

- Specific tender points

Commonly Associated Symptoms

- Irritable bowel syndrome
- Cognitive dysfunction
- Exercise intolerance
- Anxiety and reactive depression

Other Associated Symptoms

- Numbness & tingling
- Cold sensitivity
- Headaches
- TMJ dysfunction
- Raynaud's phenomenon
- Restless legs
- Dysmenorrhoea
- Irritable bladder

Differential Diagnosis

This may include:

- Polymyalgia rheumatica
- Regional myofascial pain
- Hypothyroid
- ME
- Systemic lupus
- Lyme disease
- Osteoarthritis
- Connective tissue disease

Table 1 (*citation to reference 1*)

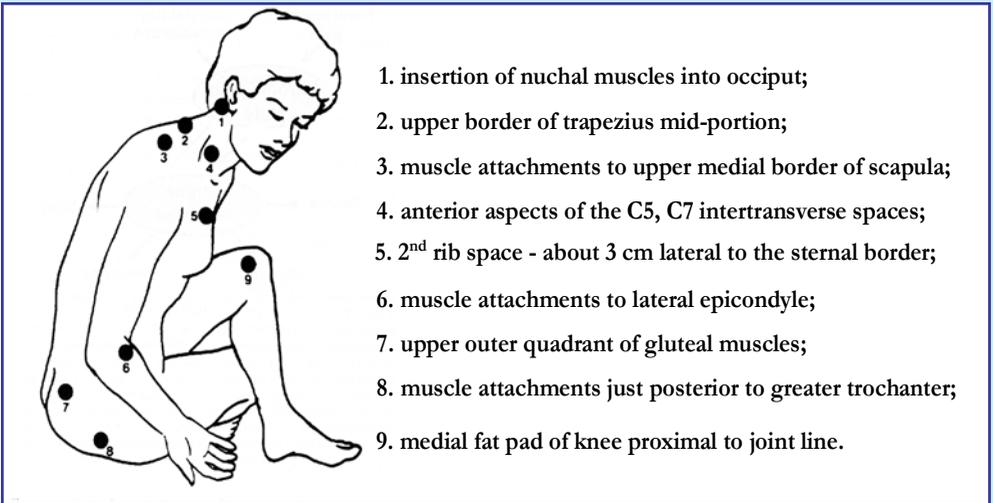
The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia⁵

History of widespread pain

Definition: pain is considered widespread when all of the following are present: pain in the left side of the body, pain in the right side of the body, pain above the waist and pain below the waist. In addition, axial skeletal pain (cervical spine or anterior chest or thoracic spine or low back) must be present. In this definition, shoulder and buttock pain is considered as pain for each involved side. “Low back” pain is considered lower segment pain.

Pain in 11 of 18 tender points sites on digital palpation

Definition: pain, on digital palpation, must be present in at least 11 of the following 18 tender points sites:



Digital palpation should be performed with an approximate force of 4 kg, as measured with a dolorimeter. For a tender point to be considered “positive” the subject must state that the palpation was painful. “Tender” is not to be considered “painful”.

For classification purposes, patients will be said to have fibromyalgia if both criteria are satisfied. Widespread pain must have been present for at least 3 months. The presence of a second clinical disorder does not exclude the diagnosis of fibromyalgia.

Table 2

Pathogenesis

The precise pathology of fibromyalgia remains unknown at present. However, current research indicates increasing evidence for the following mechanisms:

Pain amplification ⁹⁻¹²

Research clearly indicates the presence of peripheral and central sensitisation of the nervous system in fibromyalgia patients. Patients demonstrate classic signs of hyperalgesia and allodynia in response to thermal, noxious and touch stimuli. Measurements of neurotransmitter levels in the cerebrospinal fluid (CSF) have found a threefold increase in substance P together with a fourfold increase in nerve growth factor. These increases, together with continuous peripheral pain stimulation augmenting the levels of glutamate, activate the N-methyl-D-aspartate (NMDA) receptors leading to central sensitisation. The influence of the descending inhibition pathway from the brain is severely diminished by decreased levels of serotonin and noradrenaline, further augmenting the state of pain amplification.

Sleep abnormalities ^{13,14}

An intrusion of alpha waves into stage 4 delta sleep has been demonstrated using electroencephalograms. This intrusion is believed to be responsible for the non-refreshing sleep symptoms and low levels of insulin growth factor-1. A total of 80% of growth hormone is released during stage 4 delta sleep and a persistent lack of growth hormone can lead to an accumulation of biochemical and mechanical faults in the muscles and tissues of the body.

Hormone disruption ^{13,15}

Multiple hormonal disturbances have been observed in fibromyalgia. Studies show a disruption in the hypothalamus-pituitary-adrenal axis with elevated levels of corticotropin releasing hormone (CRH) and adrenal cortical-stimulating hormone in conjunction with low 24-hour urinary cortisol levels. Elevated levels of CRH lead to increased levels of somatostatin, which operates to reduce levels of thyroid hormone, growth hormone and oestrogen as well as increasing levels of prolactin. All of these imbalances have been observed to some extent in fibromyalgia patients.

Muscle pathology ¹⁶

Muscle biopsy studies have revealed the presence of “moth eaten”, ragged red fibres, type 2 fibre atrophy and decreased levels of ATP and phosphocreatine, indicating mitochondrial abnormalities and insufficient blood supply to the muscles. There is no sign of degeneration, regeneration or inflammation. Despite these observations being in unison with other chronic neuromuscular conditions and not specific to fibromyalgia, they do indicate that the muscles are involved in the overall pathogenesis. The disturbed regulation of the microcirculation and a change in the muscle metabolism might sensitise the intramuscular nociceptors. Also, the mitochondrial abnormalities may indicate a low oxidative capacity and therefore a reduced ability for endurance work. However, the pain cannot be sufficiently explained if a state of central sensitisation does not exist.

Evidence-based interventions for fibromyalgia

An interdisciplinary approach incorporating medication, activity scheduling and CBT, which addresses both physical and psychological factors, has been shown to be the optimal treatment strategy.⁴

Listening to and believing in an individual's experience of pain, together with reassurance and education, can significantly reduce worry and anxiety, which in themselves can augment the experience of pain. Pain management courses, CBT and education about fibromyalgia all address unhelpful beliefs, behaviours and their adverse effects. In addition, they encourage the acquisition and application of a range of positive coping skills and strategies. It is important that any intervention is personalised to the individual and agreed with them, so that they can take an active role in the self-management of their condition.

Pharmacological management

Patients with fibromyalgia tend to be sensitive/relatively intolerant to medications and, therefore, it is advisable to begin with low doses and to use medications with the least number of side effects. All medications should be reviewed at regular intervals to monitor their efficacy. Explaining that some side effects, e.g. those associated with tricyclics, may resolve in time can encourage the patient to persist with treatment. Also, some medications can cause weight gain, so less physically active patients may need to be advised to watch their calorie intake.

Pain

Current research points to an effective combination of tramadol hydrochloride and paracetamol (Ultracet).¹⁷ This combination affects both the ascending and descending pain pathways augmenting the release of serotonin and noradrenaline. Other analgesics like co-proxamol, co-codamol and co-dydramol may or may not be effective. There is limited evidence for the use of anti-inflammatory drugs. Low dose tricyclics, e.g. 10 mg of amitriptyline or dothiepin, and anticonvulsants, e.g. gabapentin or carbamazepine, can also prove effective for neuropathic pain.¹⁸ Muscle relaxants, e.g. baclofen, can be helpful if muscle twitching or cramps accompany the pain.¹⁸

Sleep and fatigue

Re-establishing a successful sleep routine can enhance sleep quality and reduce fatigue, improving the patient's ability to cope with other symptoms. Low-dose tricyclics, e.g. 10 mg of amitriptyline or dothiepin, can prove most effective. Tricyclics are preferable to benzodiazepine hypnotics. Benzodiazepines can be useful for initially re-establishing a sleep routine, but should never be used for more than 10–14 days because of a higher risk of psychological and physical dependence with long-term use.

Abdominal symptoms

Irritable bowel syndrome is a very common associated symptom. The use of antispasmodics, e.g. mebeverine or alverine, may reduce the spasm of the hypersensitive

bowel. Some individuals may have an intolerance to wheat and/or dairy products and excess fibre may also exacerbate the symptoms. Advise a well-balanced diet. The addition of good quality probiotics can prove useful for some patients.¹⁹

Depression

Symptoms of depression can also arise from the fear and isolation of living with chronic pain. Depression is rarely the causative factor behind fibromyalgia. Coming to terms with living with fibromyalgia and adopting changes in attitude and lifestyle is often sufficient to deal with depressive symptoms. It is important to tackle any co-existing factors that may also be contributing to the depression. In persistent cases antidepressants, e.g. tricyclics or selective serotonin reuptake inhibitors (SSRIs), can prove effective. SSRIs can be used to enhance alertness, motivation and elevate mood during the day, reducing the symptoms of fatigue, pain and apathy. SSRIs can cause restlessness and contribute to insomnia and therefore are recommended for morning administration.

Non-pharmacological management

A combination of non-pharmacological and pharmacological treatments are particularly more helpful in managing self-reported fibromyalgia symptoms and daily functioning than pharmacological treatment alone.²⁰

Emotional and behavioural management

Psychosocial factors play an important part in fibromyalgia and its successful treatment. They can also act as predictors for the outcome of intervention. “Yellow flags” is the term used by Waddell et al for psychosocial factors suggesting a poor outcome to intervention.⁸ This is on account of their tendency to augment the experience of pain, establishing a cycle of increasing pain and distress. No individual factor can be used as a reliable predictor of poor outcome, but the following factors in combination tend to do so:

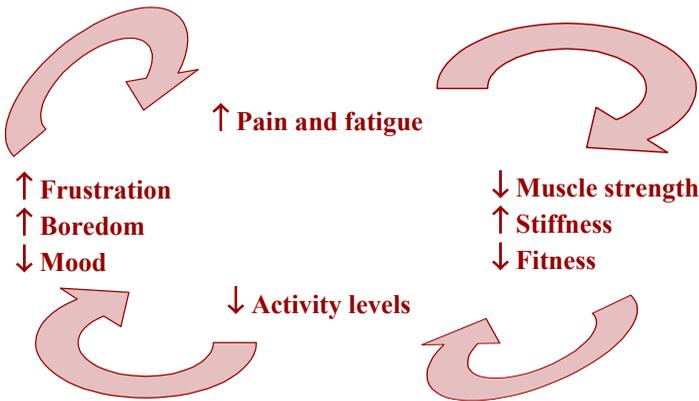
- *Belief* that pain is harmful or severely disabling
- Fear-avoidance *behaviour* (avoiding an activity through fear that it will cause pain)
- *Emotions* – tendency to low mood, withdrawal from normal social interaction
- *Expectations* of receiving passive treatment rather than active participation in a treatment programme

CBT aimed at helping patients to understand their pain and to develop coping strategies, has been shown to be most effective. CBT differs from psychotherapy, in which the patient tends to be passive while the therapist “interprets” for the patient any underlying psychological blocks. In CBT, patient and therapist collaborate to recognise unhelpful habits and behaviour, and to develop positive strategies for coping with the effects of fibromyalgia.

Body conditioning and exercise management

Fibromyalgia can impact on individuals in many ways, resulting in reduced social, emotional and physical functioning. Physical changes, such as muscle weakness and stiffness, reduced fitness and activity levels can lead to a cycle of deconditioning. Getting your patient started with an exercise programme is a means to change this downward spiral of inactivity. Some people find that they do more exercise or activities on days when they feel good, and fewer or no activities on days when they feel bad. This is often referred to as “over activity and under activity cycling” and will be discussed more in the next section.

The Deconditioning Cycle



Exercise has many known benefits such as improving fitness, aerobic capacity, mood, muscle strength, stamina, suppleness, sleep, weight, body shape and appetite.^{21,22} If your patients are unaccustomed to doing exercise, it is usual to experience unpleasant bodily or pain sensations when they start. These sensations during or after exercise do not mean that they are causing any damage to their body, and they may need some gentle encouragement to continue with their exercise despite this. In order to gradually increase their exercise and activity levels over time, a tolerance and baseline approach is most useful to encourage consistency and adherence irrespective of whether they are experiencing a “good” or “bad” day. Start with exercises that are manageable and suggest that they focus on the quality of their movement and how they are performing an exercise, rather than the quantity of what they are doing.

Example of a tolerance and baseline approach

EOD means to add one repetition every other day ED means to add one repetition every day.

| Exercise | Day 1 Tolerance | Day 2 Baseline | Day 3 | Day 4 | Day 5 | Day 6 | Day 7 | Exercise Strategy |
|----------|--------------------|-------------------|-------|-------|-------|-------|-------|----------------------|
| Stand up | 6 | 3 | 3 | 4 | 4 | 5 | 5 | +1 EOD |
| Step up | 9 | 4 | 5 | 6 | 7 | 8 | 9 | +1 ED |

Key principles of exercise management

- Exercise is a means to increase daily activity levels.
- Encourage the individual to choose a type of exercise that reflects their interests, their physical goals or specific activities they wish to return to or increase.
- A tolerance and baseline approach is the best way to get someone starting to exercise gradually over time.
- Encourage the individual to be patient and to persevere with a flexible routine they can easily incorporate into their daily lifestyle.
- If they experience difficulty continuing to exercise on a bad day, remind them that they will need to modify their exercises in order to achieve their planned number for the day. For example, doing some stretches instead, exercising with a friend, breaking the exercises up over the day or starting with the easy ones first!

A physiotherapist, with an understanding of fibromyalgia, will be able to advise your patients how to select different types of exercises according to the training effect they choose to work on. This may be in relation to physical tasks that your patients are currently struggling to do or activities that they would like to do more. Encourage them to have a go, and then they can choose which approach suits them best.

Activity scheduling, activity/rest cycling and goal setting

It is recognised (WHO²³) that occupation is a core human need that maintains health and well-being. Remaining active is an important ingredient for managing fibromyalgia. Over time, patients frequently report avoiding more and more activities that they associate with making their pain worse; or they may take this tack for a while, feel increasingly frustrated and when a “good day” comes along, they may play “catch-up” with all the activities they have put off. This way of trying to cope is understandable, common and has its own name, “activity cycling”.²⁴

However, because fatigue and poor sleep are common adjuncts to fibromyalgia, it can be helpful to manage activity in a way that uses energy wisely. Prioritising, planning and pacing activity can make a significant impact on the amount people can do in the long term. Spreading activity out over the day or the week, rather than rushing to do everything at once, breaking tasks down into manageable “chunks” and using stretches and relaxation skills during activity can all help. Patients may also need to use problem-solving skills to figure out new and creative ways of getting tasks done, within their own capabilities.

One of the barriers to continuing with activity can be the deconditioning that often occurs as muscles and joints fail to be used in the normal way because of pain. A graded exercise programme can help to gradually improve fitness, and encourage the use of the body through its full range of movements. Although aids and equipment can appear tempting, it is helpful to stress the importance of patients being able to use their own body to manage daily activity. This will raise self-esteem and guard against the stress and frustration of not coping independently. A decision about whether or not to use aids and equipment should be carefully made, and not rushed into because of the ease of a short-term solution.

If changes in activity management are to be made and sustained in the home, socially and at work, communication with family, friends and work colleagues will be important. Helping the patient to put their case for change, negotiate a way of balancing roles and responsibilities to maximise independence and working towards maximising the fun and social contact they have requires assertive communication. This is sometimes lost when pain and fatigue impact on self-confidence, but with practice can be regained and make a significant difference to enjoyment in life.

Patients sometimes find it difficult to make changes in established habits of “doing”. Engaging them in a process of trying new things, and then reporting back the benefits or costs will be part of helping them to decide on the strategies they feel able to make a part of their life. It will need to be stressed that any benefit in increased activity may be slow to happen, but that pacing has been shown to have positive effects. However, these strategies are about helping each individual to get in touch with the core values in their lives, to set goals that will move them towards their core values, and to manage each day in a way that is meaningful and productive to them.²⁵ It will not necessarily reduce pain.

Adolescents and young people with fibromyalgia

Fibromyalgia in adolescents has a different outlook. Young people have growth and development on their side. Graded exercise is very important as it is with adults. Adapting, but continuing with age-appropriate activity such as school and social life is essential. It prevents young people getting “knocked off” their growing up path and also serves as a buffer to low mood and frustration by giving opportunities for fun. Chronic pain is a serious challenge for young people, but with support and playing a “smart game” the future can be very good.

Juvenile fibromyalgia can be confused with other disorders, e.g. “growing pains”, joint hypermobility or psychological problems. However, there is one study suggesting a strong association between joint hypermobility and fibromyalgia in schoolchildren, with more girls affected than boys.²⁶

As with adults it is important to take a careful history and to acknowledge the child’s experience and description of pain. Reassuring parents who may be fearful that their child has a crippling degenerative disorder and explaining how the condition can be successfully managed is also useful.

Alternative therapies

There is limited empirical research to substantiate the use of alternative therapies. However, more focused on-going research is beginning to recognise some physiological and emotional benefits of these interventions:

- Osteopathy
- Acupuncture
- Massage therapy
- Herbal remedies

Osteopathy

Osteopathy is a system of diagnosis and treatment of a wide range of conditions. The osteopath uses his/her knowledge of anatomy, physiology and pathology combined with an in-depth evaluation of the musculoskeletal system to assess the health of the patient.

Massage therapy

Massage encourages muscle relaxation, blood flow and lymph drainage. In particular, deep-stroking massage can be used to tackle trigger points resulting from the prolonged contraction of muscle sarcomeres within a taut band of muscle. Some fibromyalgia patients will only be able to cope with a very light massage at first, needing to build up gradually.

Acupuncture

Acupuncture is commonly used for the treatment of pain and is believed to suppress hyperneural activity for short periods. There are no known side effects of this treatment, which could be beneficial to patients who are hypersensitive to pharmacological treatments.

Herbal remedies

Herbal medicine uses plant extracts for their healing properties. Popular herbs to treat fibromyalgia are ginkgo biloba, which can improve blood circulation, and valerian to help sleep and to calm nervous anxiety. Patients should appreciate that herbal remedies are medicines, which may interact adversely with prescribed medications.

Trigger points versus tender points

Tender points are the specific areas of tenderness used for the diagnosis of fibromyalgia. They produce a painful response when pressed upon, but do not refer pain to any other part of the body. Tender points usually occur in pairs so they are distributed equally on both sides of the body.

Trigger points are responsible for myofascial pain and can occur in an acute and chronic state. They are not specific to fibromyalgia, but often occur in conjunction and are magnified by pain amplification.

These highly irritable nodules of exquisite tenderness are located in a palpable taut band of muscle tissue and arise when over-stimulated sarcomeres become unable to release from their contracted state.

Trigger points always hurt when pressed upon and refer pain to other areas of the body in a predicted manner. For example, a trigger point in the sternocleidomastoid muscle refers pain to the front, top and back of the head and the jaw. Trigger points can be latent or active and can vary in irritability from day-to-day. They can cause muscle weakness and restricted range of motion as well as pain. It is important to identify symptoms that are caused by trigger points and to treat them accordingly.

A useful reference to identify the predictable patterns and treatment of trigger points is *The Trigger Point Therapy Workbook* by Clair Davies.

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www.fibromyalgia-associationuk.org The Fibromyalgia Association UK website.

www.nhsdirect.nhs.uk The NHS Direct website. From this site, click on 'health encyclopaedia', followed by 'Alphabetical Index', choose letter 'F', then select fibromyalgia.

www.ukfibromyalgia.com Website maintained by Martin Westby editor of a UK fibromyalgia magazine, FaMily Magazine.

www.myalgia.com The Oregon Fibromyalgia Foundation website, maintained by Dr Robert Bennett and his colleagues at Oregon Health Sciences University, USA.

www.myopain.org The Myopain Society website.

REFERENCE BOOKS:

A wide range of books are available from the Nutri Centre for both professionals and patients, please see website www.nutricentre.com/pages/bookshophomepage.aspx



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