

The diagnosis of fibromyalgia syndrome

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ABSTRACT

Fibromyalgia syndrome (FMS) is a common widespread primary pain condition, with a worldwide prevalence of 2%–4%. Recent research has revealed important evidence for changes in central and peripheral nervous system functions and immunological activity. The diagnosis of FMS can be challenging with no known clinical laboratory investigations to confirm or refute its presence. Symptoms are commonly multiple, fluctuant and may not easily align with established medical diagnostic categories. It can be difficult for patients to articulate their array of symptoms, and for both patients and healthcare professionals to fully make sense of the complexities of the condition. As such, patients may be diagnosed inaccurately with alternative conditions, delaying diagnosis by years. The recent publication of the Royal College of Physicians' guidance aims to support clinicians in the diagnosis of FMS. Its purpose is to provide succinct, relevant information for patients and clinicians about FMS and its diagnosis.

KEYWORDS: fibromyalgia syndrome, FMS, clinical guidelines, nociplastic pain, chronic pain

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Introduction

Fibromyalgia syndrome (FMS) is a common condition characterised by persistent and widespread pain that is associated with intrusive fatigue, sleep disturbance, impaired cognitive and physical function, and psychological distress.¹ It is classified in the International Classification of Diseases ICD-11 as chronic primary pain.¹ FMS (MG30.01) has had many names such as *fibrositis* or *fibromyositis*. It is now, however, accepted that these terms are misnomers, inaccurately implying muscle inflammation as the primary cause of pain. Although the aetiology is still abstruse, advances in research have shown that alterations in pain processing within the nervous system are likely causative.^{2,3}

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The diagnosis of FMS can be challenging as there are no clinical laboratory investigations to confirm its presence. Symptoms fluctuate and may not easily map with established medical diagnostic categories. There is, therefore, a key need to support diagnosticians in managing this condition.

Scope and purpose

This concise guideline summarises the key recommendations of the recent Royal College of Physicians' (RCP's) UK fibromyalgia syndrome guidance document on the diagnosis of adult FMS in both primary and secondary care.⁴ The guidance has been adapted to provide digestible information for clinicians and patients around a diagnostic encounter in both medical and surgical specialties. The purpose is to provide help in guiding clinicians towards improved and timely patient diagnosis and early management.

The FMS diagnostic consultation

When reviewing a patient, a number of features may signify the need to formally assess for FMS (Fig 1).

- **Widespread pain: pain in multiple regions of the body.** Patients with FMS **may not report** widespread pain, instead reporting only focal pain.⁵ It is, therefore, important to directly ask about the presence of pain elsewhere.
- **Intrusive fatigue.** This may be physical, cognitive or emotional (motivational) fatigue.
- **Hypersensitivities.** Increased sensitivity to sound, light or ambient temperature can represent changes in peripheral or central nervous system sensory processing.⁶ Widespread tenderness on clinical examination may indicate abnormal mechanical hypersensitivity.⁷
- **Longevity of symptoms.** Pain that has been present or recurrent for longer than 3 months is considered 'chronic' or 'persistent'.
- **Ineffective treatments so far.** Drug treatments are often ineffective and rehabilitation focusing solely on mobilisation or classical musculoskeletal physiotherapy may also be ineffective and can even increase pain from FMS, both suggesting that abnormal pain processing predominates.^{8–10}
- **Feeling overwhelmed (patients).** Multiple symptoms and their consequences such as disability and distress can be difficult to understand and patients often feel overwhelmed.¹¹
- **Feeling overwhelmed (clinicians).** Healthcare professionals may feel overwhelmed by the expansive symptomatology.

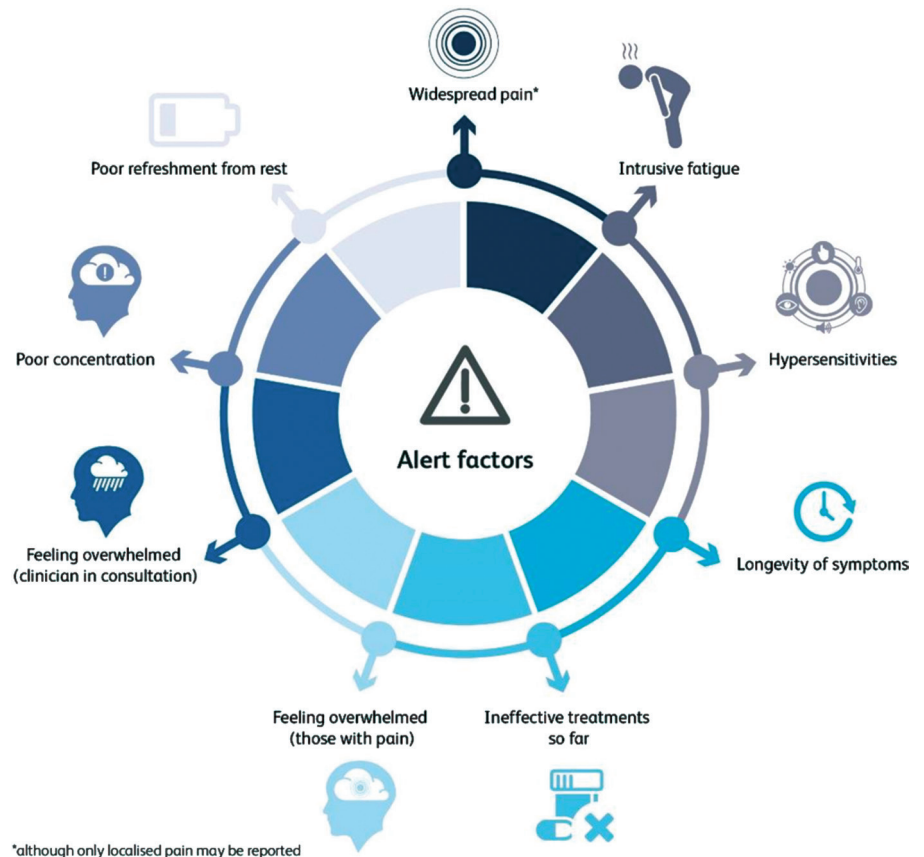


Fig 1. Fibromyalgia syndrome alert factors.

Diagnosing FMS

The diagnosis of FMS has made a departure from the specialist domain and can be initiated by physicians or practitioners who feel equipped to do so.¹² Making a diagnosis of fibromyalgia is likely to represent a significant juncture in the patient’s life and, as such, it is suggested that the clinician sets the scene appropriately (Box 1). The most recent best evidence-based guideline is the American College of Rheumatology’s (ACR’s) 2016 diagnostic criteria.¹² A diagnosis is made if the following are met (a diagnostic sheet can be found in the guidance document).⁴

- > Widespread pain index (WPI) ≥ 7 and symptom severity scale (SSS) score ≥ 5 OR WPI 4–6 and SSS score ≥ 9 .
- > Generalised pain, defined as pain in at least four of the five body regions, is present.

Box 1. Setting the scene when making the fibromyalgia syndrome diagnosis

Recommendation (evidence)

- > Acknowledge the patient’s life situation (E2)
- > Allow sufficient time (E1 + E2)
- > Arrange additional appointments or refer where needed, and explain the arrangement (E2)
- > Allow for a face-to-face diagnostic consultation if possible (E2)

Key for evidence evaluation: E1 = user or carer opinion; E2 = professional or stakeholder opinion; RA/RB/RC = research grading based on published evidence. For details see Limitations section.

- > Symptoms have been present at a similar level for at least 3 months. Patients with symptoms below this threshold may be diagnosed with FMS if above threshold symptoms were recently documented.

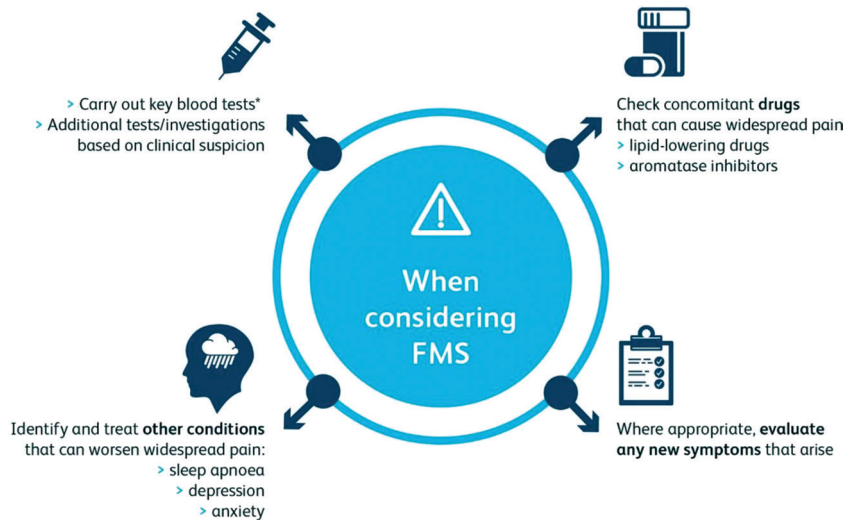
In the case of uncertainty, referral to a specialist with experience in diagnosing fibromyalgia (usually a pain specialist or a rheumatologist) is recommended.

Consideration of differentials

FMS is not a diagnosis of exclusion; it may, and often does, exist alongside other conditions (eg rheumatoid arthritis, systemic lupus erythematosus or ankylosing spondylitis). There are no specific diagnostic tests for FMS but it is recommended that treatable conditions be examined for (Fig 2).

When a diagnosis is not certain

- > Reasons for diagnostic uncertainty may include:
 - > fluctuant symptoms just below the ACR diagnostic threshold
 - > multiple health conditions (eg inflammatory conditions or depression) independently impacting the ACR WPI or SSS.
- > Symptoms evolve and it is appropriate to share any diagnostic dilemma with the patient, applying a ‘watchful waiting’ strategy.¹³
- > ‘Safety netting’ is often necessary, by sharing important clinical symptoms or signs with the patient that may indicate alternate diagnoses.



* Blood tests should include: full blood count, erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP), creatine kinase (CK), liver function tests (LFT), thyroid stimulating hormone (TSH), glucose, urea and electrolytes (U&Es).

Fig 2. Considering and investigating differentials and multiple health conditions.
FMS = fibromyalgia syndrome.

- > Sensitisation does not have temporal linearity, ie there is no evidence that sub-threshold symptoms will always progress to an FMS diagnosis.¹⁴
- > Diagnostic uncertainty should not preclude agreeing a shared plan using the best evidence for the management of chronic pain.

Clinical management

Clinical management is beyond the scope of this diagnostic guideline and is covered elsewhere, but some general principals are suggested (Box 2).¹⁵

FMS and perioperative care specific to surgical practice

FMS is a common condition, and while FMS pain is not itself amenable to surgery, many patients with FMS will undergo surgery. Nociceptive pain (pain due to mechanical or inflammatory stimuli) may be amenable to surgery. Neuropathic

pain (pain caused by a lesion to the nervous system) may sometimes be amenable to surgery. However, most chronic pains are *neither* nociceptive nor neuropathic. Their mechanism is termed *nociplastic*, whereby abnormal pain processing is primarily responsible.^{2,16}

When practising in surgery, there are some important alert factors to suggest that the pain may be nociplastic (Box 3). If nociplastic pain, or FMS is suspected, the direction of referral following surgical assessment will depend on the local situation, and may include going back to the GP or to a pain clinic. In this situation, patient communication is vital and may require finesse in surgery as much as in medicine (Box 4).

Box 2. Clinical management and essential information

Recommendation (evidence)

- > Management of pain, including management with information, rehabilitative methods and connection with non-clinical support groups can reduce suffering. This should be done in parallel to investigation (E1+E2)
- > Established pain medications or normal musculoskeletal physiotherapy are often not effective or can even cause harm and the patient should be advised accordingly^{8,15-17} (E1+E2, RA)
- > FMS is a long-term condition, sometimes requiring planned reviews in primary or secondary care. Development of a therapeutic relationship is crucial if expertise from both clinician and patient is to be effectively utilised in a shared management plan^{16,18} (E1+E2, RB)

Box 3. Fibromyalgia syndrome alert factors in practice

Recommendation (evidence)

- Pain
 - > Pain out of proportion to pathology now, or in the patient's history, either in the currently painful or other body regions (E2)
 - > Chronic pain in more than one location¹⁴ (RC)
- Effectiveness of treatment for pain
 - > Pain not improving with prior surgeries for this or other problems. This includes pain recurrence both immediately or months after surgery (E2)
 - > History of repeated surgeries for this or other painful problems (E2)
 - > Medication treatment or physiotherapy not effective or even worsening pain^{8,17} (E2, RC)
- Other factors
 - > Presence of fatigue, non-refreshing sleep, psychological distress and cognitive decline (such as short-term memory problems or problems with thinking) (E2, RC)
 - > High perioperative pain, and high analgesia requirements in earlier operations²⁰⁻²² (E2, RB)

Box 4. Communication with your patient and other healthcare professionals

Recommendation (evidence)

- a) What to say to your patient
 - State the reason for the referral (why is the patient here) (E1+E2)
 - State that you can exclude the surgical cause, and explain why (E1+E2)
 - State that this does not mean that there is no reason for their pain (E1+E2)
 - If you suspect that this could be nociplastic pain, then explain this to the patient and provide them with a nociplastic pain information leaflet⁴ (E1+E2)
- b) What to include in the clinic letter
 - Mention suspected nociplastic pain or FMS within the clinic letter. This will provide important information to other healthcare professionals (E2)
 - Clarify that the specific surgical cause for their pain has been excluded (E1+E2)
- c) What not to say to your patient
 - 'There is no reason for your pain' (E1+E2)
 - 'There is nothing wrong with you' or 'I can't find anything wrong with you' (E1+E2)
 - 'It is all in your head' (E1+E2)
 - 'It is psychological' (E1+E2)
 - 'There is nothing we can do', without providing further information (E1+E2)
 - 'There is nothing anyone can do' (E1+E2)

Decision to operate

Patients with FMS often respond to surgical interventions differently to patients without FMS with a similar lesion and their management may benefit from the involvement of a multidisciplinary team. It should be noted that failure to relieve pain with surgery may often only become apparent many months afterwards, because surgery may evoke a significant placebo response, and some types of anaesthetic may temporarily diminish nociplastic pain by reducing central sensitisation.¹⁷ The true long-term effect of surgery on pain is impossible to gauge outside clinical trials. Pain increase post-surgery may also reflect an independent FMS pain flare.

Patients without a formal diagnosis of FMS

Surgeons should be aware that patients who have some features of FMS (even if these do not trigger a formal diagnosis of FMS) may achieve poorer pain relief from surgery.^{18,19} Patients with *mostly regional pain* (eg painful knee osteoarthritis) may possess symptoms akin to FMS such as fatigue, hypersensitivity to sensory stimuli, poor sleep, poor memory or psychological distress, without meeting FMS criteria.¹¹ The causes for these symptoms are unknown and they are not considered psychological, although psychological distress is often present.

The degree of symptomatology is thought to relate to the degree of nervous system sensitisation. Research indicates that even below the threshold for diagnosis, surgical outcomes may be affected: as a group, patients with high scores are likely to be at

risk of poor pain improvement following surgery.²⁰ Conversely, the response to surgery among patients with high sensitisation scores is diverse and many patients do have good outcomes. Six months after knee or hip replacement surgery, two-thirds of patients with *high preoperative sensitisation scores, but not FMS*, reported improvement in regional pain but also in generalised symptoms, such as fatigue and poor sleep.²¹ However, the remaining one-third experienced either no improvement or, worse, an increase in pain following their operation. Sadly, no reliable tool yet exists to predict surgical responders.

Limitations

The guidance was compiled using the standards set out by the AGREE collaboration.²² A methodology table is available online with a comprehensive description of the procedure in the main RCP guidance document.⁴ The recommendations were formulated through panel consensus, considering the existing literature. Randomised controlled trial (RCT) data were used as a priority. However, due to a paucity of RCT-based evidence specifically informing diagnosis and management, many of the recommendations were based on the expert opinion of service users (E1) and professionals (E2); as per the national service framework for long-term conditions.²³ Where research exists, this is denoted RA (high quality), RB (medium quality) or RC (low quality), as detailed in the guidance methodology.⁴ This guidance refers to the adult population.

Implications for implementation

For the physician, be cognisant of alert features of FMS in consultations. When making a diagnosis of FMS use the ACR 2016 criteria.¹² FMS may coexist with other medical conditions and a diagnosis can be made with detailed history and examination in conjunction with standard blood tests to exclude other treatable conditions. **For the surgeon**, when considering the appropriateness of a patient for surgery, be aware of alert features of FMS and nociplastic pain. If a patient with FMS presents for surgery to treat pain, consider whether their pain is amenable to surgery and communicate this effectively. If surgery is indicated, involvement of the multidisciplinary team may be helpful for optimal outcomes. ■

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