

Appendices

Appendix 1:

Assessment Tools, Investigations, and Management Approaches for Fibromyalgia

ACR Diagnostic criteria for fibromyalgia syndrome^{1,19}

A patient satisfies diagnostic criteria for fibromyalgia if the following 3 conditions are met:

**1) Widespread pain index (WPI) ≥ 7 and symptom severity (SS) scale score ≥ 5 or
Widespread pain index (WPI) 4-6 and symptom severity (SS) scale score ≥ 9**

2) Generalised pain: Pain must be present in at least 4 of 5 regions

Jaw, chest, and abdominal pain are not included in the generalised pain definition

3) Symptoms have been present for at least 3 months

A diagnosis of fibromyalgia is valid irrespective of other diagnoses. A diagnosis of fibromyalgia does not exclude the presence of other clinically important illnesses

Ascertainment:

1) WPI

Note the number of areas/regions in which the patient has had pain **over the last week**. In how many areas has the patient had pain?

(Score will be between 0 and 19)

Region 1: Left Upper Region

- Jaw, left *
- Shoulder girdle, left
- Upper arm, left
- Lower arm, left

Region 2: Right Upper Region

- Jaw, right *
- Shoulder girdle, right
- Upper arm, right
- Lower arm, right

Region 3: Left Lower Region

- Hip (buttock, trochanter), left
- Upper leg, left
- Lower leg, left

Region 4: Right Lower Region

- Hip (buttock, trochanter), right
- Upper leg, right
- Lower leg, right

Region 5: Axial Region

- Neck
- Upper back
- Lower back
- Chest *
- Abdomen *

* Not included in the generalised pain definition

2) SS scale score

The SS scale score is the sum of the severity of the 3 symptoms (fatigue, waking unrefreshed, cognitive symptoms) plus the sum of the number of 3 symptoms (headaches, pain or cramps in lower abdomen, depression).

(The final score is between 0 and 12)

For each of the 3 symptoms below, indicate the level of severity over the past week using the following scale:

0 = no problem

1 = slight or mild problems, generally mild or intermittent

2 = moderate, considerable problems, often present and/or at a moderate level

3 = severe: pervasive, continuous, life-disturbing problems

Fatigue (0-3)

Waking unrefreshed (0-3)

Cognitive symptoms (0-3)

During the previous 6 months indicate the number of the following symptoms the patient has been bothered by:

- Headaches (0-1)
- Pain or cramps in lower abdomen (0-1)
- Depression (0-1)

The fibromyalgia severity (FS) scale is the sum of the WPI and the SS scale

3) ACTTION-APS Pain Taxonomy (AAPT) Diagnostic Criteria for fibromyalgia⁴:

- Multisite pain defined as 6 or more pain sites from a total of 9 possible sites:
 - Head
 - Left arm
 - Right arm
 - Chest
 - Abdomen
 - Upper back and spine
 - Lower back and spine, including buttocks
 - Left leg
 - Right leg
- Moderate to severe sleep problems or fatigue
- Multisite pain plus fatigue or sleep problems must have been present for at least 3 months.

The presence of another pain disorder or related symptoms does not rule out fibromyalgia.

Appendix 2:
**Disorders that can Mimic and/or Overlap with Fibromyalgia Along with
Characteristic Clinical Features that Differentiate Them from Fibromyalgia¹⁰**

Disorders	Differentiating clinical features
Rheumatoid arthritis, Systemic Lupus Erythematosus and Sjögren's syndrome	<p>Characteristic synovitis and systemic features of connective tissue disease, apart from musculoskeletal pain, fatigue, Raynaud phenomenon, dry eyes and dry mouth, are usually not features of fibromyalgia.</p> <p>Routine serologic tests are not recommended because of low positive predictive value.</p>
Ankylosing spondylitis and other inflammatory back conditions	<p>Generally, there is normal spinal motion in fibromyalgia.</p> <p>Characteristic radiologic features of these disorders are not present in fibromyalgia.</p> <p>Anyone under the age of 45 with 3+ months of significant early morning back stiffness which improves with activity and worsens with rest or who is woken in the second half of the night with back pain or who has alternating buttock pain should be referred to rheumatology even if they have normal spinal movements and a normal x-ray.</p>
Polymyalgia rheumatica (PMR)	<p>Tender points are not always present in PMR. Stiffness is more prominent than pain in PMR.</p> <p>Most patients with PMR have a raised CRP/ESR (erythrocyte sedimentation rate), while it is normal in fibromyalgia.</p> <p>(Expert Reviewer comment: Patients with PMR respond extremely well to modest doses of corticosteroids, in contrast to fibromyalgia patients. Patients with fibromyalgia may feel somewhat better after steroids, but those with PMR will feel completely back to normal within 1 to 2 weeks of starting steroids.)</p>
Inflammatory myositis and metabolic myopathies	<p>Myositis and myopathies can cause muscle weakness and muscle fatigue, but they are not usually associated with diffuse pain.</p> <p>Patients with myositis or myopathies have abnormal muscle enzyme tests and specific histopathologic findings on muscle biopsy, in contrast to fibromyalgia patients.</p>

Disorders	Differentiating clinical features
Statin myopathy	<p>Statin myopathy symptoms are limited to muscle weakness and pain without other symptoms associated with fibromyalgia.</p> <p>Statin myopathy pain is temporally associated with statin therapy.</p> <p>Statin myopathy can be associated with abnormal muscle enzyme tests.</p>
Infection: <ul style="list-style-type: none"> Chronic viral infection (e.g. infectious mononucleosis) HIV (Human Immunodeficiency Virus) HTLV (Human T-Lymphotropic Virus) HBV (Hepatitis B Virus) HCV (Hepatitis C Virus) Lyme disease, Long COVID (Coronavirus Disease) 	In fibromyalgia patients there is no objective evidence of inflammation or organ system dysfunction.
Hypothyroidism	Although thyroid autoantibodies are common in fibromyalgia patients, thyroid function tests are usually normal.
Hyperparathyroidism	Hypercalcemia is not present in fibromyalgia.
Cushing's syndrome	<p>Cushing's syndrome is associated with muscle weakness rather than pain.</p> <p>The characteristic facial and skin signs of Cushing's syndrome are not present in fibromyalgia.</p>
Adrenal insufficiency	Adrenal insufficiency causes severe exhaustion, while it is not typically associated with chronic widespread pain.
Hypophosphatasia	Most hypophosphatasia patients have low alkaline phosphatase.
Neurologic diseases: <ul style="list-style-type: none"> Peripheral neuropathies Cervical radiculopathy Entrapment syndromes (e.g. carpal tunnel syndrome) Multiple sclerosis Myasthenia gravis 	<p>Multiple sclerosis and myasthenia gravis are associated with post-exercise muscle and generalised fatigue, but not with widespread pain.</p> <p>Thorough neurologic examination can reveal neurologic signs characteristic of specific diseases.</p>

Disorders	Differentiating clinical features
Myofascial pain syndromes - they may include other common regional pain disorders such as: <ul style="list-style-type: none"> • Tension headaches • Occupational overuse syndrome • Cumulative trauma disorder • Work related musculoskeletal disorder • Idiopathic low back and cervical strain disorders • Chronic pelvic pain • Temporomandibular disorder and interstitial cystitis 	In myofascial pain syndromes the pain and the tenderness are confined in one anatomic region.
Psychiatric disorders: <ul style="list-style-type: none"> • Depression • Anxiety disorders, • Posttraumatic stress disorder 	In fibromyalgia patients with a concurrent psychiatric disorder, the attribution of symptoms to fibromyalgia or the psychiatric disorder is not always possible.
Sleep disorders: <ul style="list-style-type: none"> • Obstructive sleep apnoea • Restless legs syndrome • Periodic limb movement disorders 	<p>Detail history can identify most of the primary sleep disorders.</p> <p>Chronic widespread pain is uncommon in primary sleep disorders.</p>
Irritable bowel syndrome	According to the 2009 American College of Gastroenterology recommendations for the diagnosis of irritable bowel syndrome, it is defined by abdominal pain or discomfort that occurs in association with altered bowel habits over a period of at least three months.
Temporomandibular disorders	Temporomandibular disorders are characterized by recurrent facial/jaw pain and/or limitation in jaw opening occurring in the past six months.
Tension – Migraine headache	Tension – migraine headache is characterized by recurrent headaches (at least five for migraine, at least 10 for tension-type) lasting 30 minutes.
Interstitial cystitis	According to the American Urological Association guidelines interstitial cystitis is defined as an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes.

Appendix 3: For clinicians - Fibromyalgia syndrome: the essentials



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For clinicians



Fibromyalgia syndrome: the essentials

What is fibromyalgia syndrome (FMS)?

- ▶ FMS is a medical condition that causes widespread pain, fatigue and difficulty concentrating
- ▶ It is multifactorial with neurophysiological, immunological and cognitive elements
- ▶ It responds poorly to conventional treatments, including medicines and injections
- ▶ It is best managed with an individualised multi-element support plan



What to look for

- ▶ Pain treatment is ineffective – 'nothing works'
- ▶ Significant distress
- ▶ Multiple symptoms over time
- ▶ Other conditions such as IBS, headache, abdominal or pelvic pain
- ▶ Pain out of proportion to what would usually be expected



Screen for other pathologies

- ▶ History and examination:
 - rheumatological, endocrine or neurological conditions
 - obstructive sleep apnoea
 - chronic fatigue syndrome/ME
 - depression
- ▶ Review and examine medication
- ▶ Lab tests based on clinical suspicion, but should include:
 - full blood count
- ▶ ESR/C-reactive protein
- ▶ urea and electrolytes (U&Es)
- ▶ liver and bone profile
- ▶ creatinine kinase
- ▶ blood glucose
- ▶ thyroid stimulating hormone

- ▶ Remember: FMS is not a diagnosis of exclusion; it can also coexist with other conditions



How to diagnose

- ▶ Ideally, carry out a face-to-face assessment
- ▶ Symptoms should be present for >3 months
- ▶ Use ACR (American College of Rheumatology) criteria to aid diagnosis
- ▶ Use symptom severity index (SSI)* to score fatigue, concentration, refreshment from rest and presence of abdominal pain, depression and headache
- ▶ Use widespread pain index (WPI)* to score pain in four body quadrants plus axial region
- ▶ Does it sound right? ie not unilateral or upper/lower body pain only
- ▶ Symptoms cannot be explained by any other conditions



What to say

- ▶ First of all, listen, supportively
- ▶ Share information and signpost to links
- ▶ Share decisions on management and support planning
- ▶ Help coordinate an individualised support plan based on goals and skills

*FMS diagnosis requires a WPI score ≥ 7 and SSI score ≥ 5 or WPI 4–6 and SSI ≥ 9 , with pain in 4/5 body regions

Appendix 4: For patients – Fibromyalgia syndrome: the essentials



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Fibromyalgia syndrome: the essentials

For patients



What is fibromyalgia syndrome?



- Fibromyalgia syndrome (FMS) is real
- It causes pain from typically non-painful things
- It is a condition that changes the way the nervous system processes sensory signals; pain can result from this
- It is not a degenerative, age-related or psychological condition

What can I expect to feel?

You are likely to experience some, but not necessarily all, of these symptoms:

- Widespread pain without an injury
- Old or healed injuries can hurt
- No energy or struggling to recharge
- Difficulty with getting to sleep or staying asleep
- Trouble concentrating or remembering things
- Frustrated, worried or low in mood
- Changeable symptoms – things can worsen or improve, sometimes without warning

How is it diagnosed?

- There are no X-rays, scans or blood tests that can check for fibromyalgia
- Your clinician will decide with you whether you need tests to rule other things out
- There are detailed criteria used to help diagnose FMS – your clinician will share these with you
- A diagnosis can be made when a pattern of symptoms occur



What can I do?



- Get to know about the condition – find and use as many good resources as you can – share them with those around you to help them understand too
- Be really honest with yourself – ask yourself 'How do I know my pain medicines are helping?' and 'How can I do the best I can to look after myself physically and mentally?'
- Develop your support team – get to know what you need from people around you, and keep those you know help you close
- Be open with people about what you need from them
- Be curious about what helps – your toolbox is yours and no one else's
- Be focused and realistic with healthcare professionals to make the best use of your time together – plan ahead what you want from the consultation and discuss this at the start

Appendix 5: Additional Resources/web links

Fibromyalgia Action UK

FMA UK – Info Booklets

A range of information booklets are available, and individuals can download PDF copies of them. They are filled with information regarding fibromyalgia, ranging from the symptoms of the condition to the impact that it can have on employment. They are suitable for both newly diagnosed or people looking for more information

Live Well with Pain

Home – Live Well with Pain

This website is all about learning new approaches and skills to help individuals live well, despite persistent pain. Many tools and resources are available, both for practitioners and people with pain.

Pain Association Scotland

Pain Association

A national charity that delivers professionally led self-management pain education in the community. The website has links to what is happening in your geographical area as well as other resources such as videos