Bone pain isn't usually listed as a primary feature of Myalgic Encephalomyelitis (ME), but many patients do report it. Here's how it can fit into the disease picture:

Why Bone Pain Can Occur in ME

1. Neuroinflammation & Central Sensitization

* ME involves dysfunction in the central nervous system, with evidence of neuroinflammation.

* This can heighten pain perception and cause patients to feel pain more intensely, even in bones or joints.

2. Immune Dysregulation

* ME is characterized by chronic immune activation, including abnormal cytokine profiles.

* Pro-inflammatory cytokines (like IL-1, IL-6, TNF-α) can stimulate pain pathways and cause deep, aching bone or marrow-like pain.

3. Mitochondrial Dysfunction & Hypoperfusion

* Reduced energy metabolism in muscle and bone tissue may lead to localized ischemia or metabolic stress, felt as deep musculoskeletal pain.

4. Co-occurring Conditions

* Fibromyalgia (common overlap with ME) can cause widespread musculoskeletal pain, including deep bone aches.

* Orthostatic intolerance (low blood flow, poor oxygen delivery) may also contribute to limb heaviness and pain.

* Some patients develop osteopenia/osteoporosis from immobility, malnutrition, or medications, which can cause bone pain.

Descriptions from Patients

* "Deep bone ache" especially in legs, hips, ribs, or spine.

* Pain worsening after post-exertional neuroimmune exhaustion (PENE/PEM).

* Night-time bone pain disturbing sleep.

* Distinction from muscle pain: feels deeper, as if inside the marrow.

What to Do

* Document bone pain clearly for clinicians, noting location, timing, and triggers (exertion, orthostatic stress, infections, cold weather).

* Ask for screening if pain is severe or progressive:

* Bone density scan (DEXA)

* Vitamin D, calcium, phosphate levels

* Inflammatory markers

* Pain management in ME is complex, but strategies sometimes used include low-dose naltrexone (LDN), neuropathic pain meds, and pacing to prevent flare-ups.

Bone pain isn't a "defining" hallmark of ME, it is a recognized symptom in subsets of patients, likely reflecting the neuroimmune and metabolic dysfunction underlying the illness.

Together, these references show that bone pain (or deep marrow-like aching) is reported in ME, linked to immune activation, atypical pain processing, and exertion intolerance.

Pain in ME

* Carruthers BM, van de Sande MI, De Meirleir KL, et al. (2011). Myalgic Encephalomyelitis: International Consensus Criteria. Lists widespread pain including "muscle, joint, abdominal, or chest pain" and notes that it can be "atypical in pattern and severity," often described as deep aching pain. https://pubmed.ncbi.nlm.nih.gov/21777306/

Bone & Deep Pain Reports

* Nacul LC, Lacerda EM, Kingdon CC, et al. (2019). How myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) progresses: The natural history of ME/CFS.Patients describe deep, aching pain involving muscles and bones, often worsened by exertion. https://pmc.ncbi.nlm.nih.gov/articles/PMC7431524/

* Carruthers BM, Jain AK, De Meirleir KL, et al. (2003). Canadian Consensus Criteria for ME/CFS. Notes pain can be migratory, atypical, and include deep bone pain as part of the illness spectrum. PDF – ME/CFS Canadian Criteria https://rme.nu/.../uploads/2023/06/Canadian-definition-2.pdf

Immune & Cytokine Links to Bone Pain

* Montoya JG, Holmes TH, Anderson JN, et al. (2017). Cytokine signature associated with disease severity in ME/CFS. Elevated pro-inflammatory cytokines (IL-1, IL-17, TNF-α) known to cause deep musculoskeletal and bone-like pain. https://pubmed.ncbi.nlm.nih.gov/28760971/

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