

## Types of pain in ME. Part 2

Neuropathic pain is a type of pain that originates from damage or dysfunction in the nervous system itself, rather than from tissue injury like a cut or bruise. In other words, the nerves are sending abnormal signals to the brain that are perceived as pain, even when there is no ongoing injury. Neuropathic pain is different from regular muscle or joint pain, because it is directly caused by nerve signals going wrong, not by tissue damage

- \*Burning, stabbing, or “electric shock” sensations.
- \*Tingling, numbness, or crawling (“paresthesia”).
- \*Heightened pain from normally non-painful stimuli (allodynia).
- \*Linked to peripheral nerve dysfunction.

Some ME patients experience neuropathic pain as part of peripheral nerve dysfunction, possibly due to immune or viral effects on nerves. Common locations: hands, feet, or sometimes widespread. Often triggered or worsened by exertion, sensory input, or stress.

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## Bone and Deep Tissue Pain

### Characteristics of Bone or Deep Tissue Pain

#### Quality of Pain

- \*Deep, aching, or throbbing.
- \*Sometimes described as “heavy” or “pressure-like.”
- \*Can feel like it’s under the surface, not superficial.
- \*Often constant but may fluctuate in intensity.

#### Distribution

- \*Can affect multiple sites: spine, pelvis, ribs, long bones of arms and legs.
- \*May coexist with muscle and joint pain, making it hard to distinguish the exact source.
- \*Sometimes localized in one area, particularly if there’s inflammation or nerve involvement nearby.

#### Triggering and Exacerbating Factors

- \*Physical exertion: Even minor activity can worsen pain.

\*Post-exertional neuroimmune exhaustion (PENE): Pain often peaks 12 to 72 hours after activity.

\*Infections or immune activation: Viral or bacterial triggers may flare deep tissue pain.

\*Prolonged rest or inactivity can sometimes worsen stiffness and aching.

#### Temporal Pattern

\*Pain may be constant but fluctuates in intensity.

\*Often worsens during disease flares or relapses.

\*Can persist for weeks or months during chronic disease stages.

#### Possible Mechanisms

The exact causes are not fully understood, but several factors may contribute:

\*Microcirculatory dysfunction: Reduced oxygen or nutrient delivery to bones and deep tissues may cause pain.

\*Immune system dysregulation: Chronic inflammation or cytokine activity may sensitize pain pathways.

\*Neuropathic mechanisms: Nerve dysfunction may amplify perception of deep tissue pain.

\*Musculoskeletal strain: Weak muscles or postural abnormalities may increase pressure on bones and connective tissue.

#### Associated Features

\*Deep tissue tenderness to palpation.

\*Feeling of “heaviness” or soreness after minimal activity.

\*Often accompanies fatigue, cognitive dysfunction, and post-exertional malaise.

\*Sometimes described alongside bone marrow discomfort or generalized malaise.

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Abdominal and visceral pain in Myalgic Encephalomyelitis (ME) is common but often overlooked. Unlike superficial pain, visceral pain arises from internal organs and is often diffuse, difficult to localize, and accompanied by other gastrointestinal or autonomic symptoms.

#### Characteristics of Abdominal and Visceral Pain

##### Quality of Pain

- \*Cramping, aching, or pressure-like discomfort.
- \*Can be sharp or stabbing at times, but usually dull and diffuse.
- \*Often described as “deep inside” or “internal heaviness.”
- \*Frequently fluctuates in intensity.

#### Distribution

- \*Usually generalized across the abdomen but can localize to the lower abdomen, upper abdomen, or sides.
- \*Can involve pelvic organs, particularly in women, causing urinary or reproductive discomfort.
- \*Often associated with intestinal bloating, gas, or gut motility issues.

#### Triggering and Exacerbating Factors

- \*Dietary triggers: Certain foods, sugar, gluten, or lactose may worsen pain.
- \*Gut dysbiosis or SIBO (small intestinal bacterial overgrowth) can amplify discomfort.
- \*Infections or immune activation: Flare-ups of viral or bacterial activity can worsen visceral pain.
- \*Stress or autonomic dysregulation can increase abdominal cramping or gut sensitivity.
- \*Physical exertion may worsen abdominal discomfort indirectly through post-exertional malaise.

#### Temporal Pattern

- \*Pain may be intermittent or persistent.
- \*Often worse after meals or at certain times of the day.
- \*Can fluctuate with disease activity and energy levels.

#### Possible Mechanisms

- \*Autonomic dysfunction: ME often affects the autonomic nervous system, leading to gut motility issues, blood flow abnormalities, and visceral hypersensitivity.
- \*Immune dysregulation: Chronic low-grade inflammation in the gut or systemic cytokine activity may sensitize internal organs.
- \*Microbiome disturbances: SIBO, altered gut flora, or bile acid malabsorption can contribute to cramping and bloating.

\*Peripheral nerve sensitization: Visceral nerves can become hyper-responsive, causing heightened pain perception.

#### Associated Symptoms

\*Bloating, gas, or distension.

\*Nausea, sometimes with mild vomiting.

\*Changes in bowel habits: diarrhea, constipation, or alternating patterns.

\*Pain often overlaps with fatigue, cognitive dysfunction, and post-exertional malaise.

\*Can coexist with other ME pain types like muscle or deep tissue pain.

#### Management Considerations

\*Dietary modifications: Low FODMAP, avoiding trigger foods, or personalized nutrition plans.

\*Probiotics or antibiotics for SIBO under medical supervision.

\*Gentle pacing to reduce post-exertional exacerbation of gut symptoms.

\*Hydration and electrolyte balance to support gut motility.

\*Symptom-targeted medications (e.g., antispasmodics) may provide temporary relief but should be used carefully

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#### Skin and Surface Pain in ME

##### Description

\*Tenderness or hypersensitivity: Even light touch, gentle pressure, clothing, or bed sheets can trigger pain.

\*"Sunburned skin" sensation: Skin may feel raw, hot, or burning without visible redness or rash.

\*Localized or widespread: Some patients experience it in specific areas (arms, legs, torso), while others report more diffuse discomfort.

##### Characteristics

\*Pain is often neuropathic or central in origin, meaning the nerves or brain overreact to normally harmless stimuli.

\*Sometimes described as stinging, tingling, or electric shock-like sensations.

\*Can fluctuate with energy levels, stress, or post-exertional malaise.

## Triggers and Exacerbating Factors

- \*Clothing or bedding: Tight fabrics, seams, or sheets can worsen pain.
- \*Temperature changes: Cold, heat, or sudden drafts may increase sensitivity.
- \*Physical activity or minor trauma: Even light movement or bumping into objects can trigger discomfort.
- \*Sensory overload or stress: Can heighten perception of skin pain.

## Possible Mechanisms

- \*Cutaneous allodynia: The nervous system perceives normally non-painful stimuli as painful.
- \*Peripheral nerve sensitization: Small fiber neuropathy or other peripheral nerve dysfunction may be involved.
- \*Central sensitization: The spinal cord and brain amplify pain signals, causing exaggerated perception of surface stimuli.
- \*Immune system dysregulation: Inflammatory cytokines may increase nerve sensitivity.

## Associated Features

- \*Sometimes coexists with neuropathic pain, muscle pain, or joint pain.
- \*Can make simple tasks like dressing, showering, or lying in bed uncomfortable.
- \*May fluctuate daily or worsen during ME flares or post-exertional malaise.

## Management Considerations

- \*Loose, soft clothing and smooth bedding to minimize friction.
- \*Temperature control: Avoid extremes of heat or cold.
- \*Pacing and energy management to reduce flares.
- \*Topical treatments (cool compresses, gentle creams) can provide temporary relief.
- \*Pain medications or neuropathic agents may help, but effectiveness varies.

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## Throat and Glandular Pain in ME

### Description

- \*Sore throat without infection: The throat can feel raw, scratchy, or “tight,” but there may be no redness, swelling, or signs of infection.

\*Tender lymph nodes: Lymph nodes in the neck, underarms, or groin may feel swollen, heavy, or sore.

\*Sensation: Some patients describe it as a “fullness,” “pressure,” or mild ache deep in the throat or neck region.

#### Common Locations

\*Neck: Front and sides of the neck where lymph nodes are located.

\*Underarms or groin: Sometimes lymph nodes here are tender during flares.

\*Throat: Around tonsils, pharynx, or base of the tongue.

#### Triggers and Exacerbating Factors

\*Post-exertional Neuroimmune exhaustion (PENE): Physical or cognitive exertion often worsens throat and lymph node pain.

\*Infections or immune activation: Viral or bacterial triggers may flare these symptoms.

\*Stress or sensory overload: Can amplify perception of pain.

\*Temperature extremes: Cold or sudden drafts may increase discomfort in some patients.

#### Possible Mechanisms

\*Immune system dysregulation: Chronic immune activation can cause lymph nodes to become tender even without infection.

\*Low-grade inflammation: Cytokines may sensitize the throat and lymph nodes.

\*Autonomic dysfunction: Can contribute to swelling or a sensation of “pressure” in the neck and throat region.

#### Associated Features

\*Often occurs alongside fatigue, flu-like malaise, post-exertional crashes, or muscle/joint pain.

\*May fluctuate daily or worsen during ME relapses.

\*Some patients notice mild throat discomfort even at rest, which intensifies after exertion.

#### Management Considerations

\*Hydration: Warm or room-temperature fluids can soothe discomfort.

\*Soft foods: Avoid hard, scratchy, or acidic foods if sore.

\*Pacing: Limit physical, cognitive, or sensory exertion to reduce flares.

\*Rest: Gentle neck support and low-stimulation environments help.

\*Symptom-targeted therapy: Occasionally, gentle pain relievers or anti-inflammatory approaches may be used under medical guidance.

\*Avoid unnecessary antibiotics: Often these symptoms are not caused by infection, so antibiotics are usually not needed.

This type of pain is distinct from typical sore throats caused by infection, and recognizing it as part of ME can help patients avoid unnecessary tests or treatments.

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## Spinal, Back, and Neck Pain in ME

### Description

\*Stiffness or aching: Pain may feel deep, dull, or pressure-like along the spine, particularly in the neck and upper back.

\*Restricted movement: Some patients experience difficulty turning or bending the neck or back due to stiffness or pain.

\*Associated sensations: Can include muscle tension, tightness, or a feeling of “heaviness” along the spine.

### Common Locations

\*Neck: Base of the skull, cervical spine, and surrounding muscles.

\*Upper back: Between the shoulder blades, thoracic spine.

\*Lower back: Lumbar region, sometimes extending into hips or buttocks.

### Triggers and Exacerbating Factors

\*Poor posture: Sitting or standing for extended periods can worsen pain.

\*Minimal exertion: Even light lifting, reaching, or bending can trigger discomfort.

\*Prolonged inactivity: Long periods of lying or sitting may increase stiffness.

\*Post-exertional Neuroimmune exhaustion (PENE): Pain may spike 12 to 72 hours after physical or cognitive activity.

\*Stress and tension: Emotional stress can increase muscle tightness and spinal pain.

### Possible Mechanisms

\*Muscle fatigue or weakness: Weak muscles around the spine can increase strain and discomfort.

\*Microcirculatory or vascular issues: Poor blood flow may contribute to aching or heaviness.

\*Neuropathic or central sensitization: Heightened nerve sensitivity may amplify pain signals.

\*Postural or biomechanical strain: Small misalignments or repetitive movements may exacerbate pain.

#### Associated Features

\*Can contribute to headaches, particularly tension-type or cervicogenic headaches.

\*May cause dizziness, lightheadedness, or balance issues if neck muscles are tight.

\*Can limit mobility and make simple activities like turning the head, getting out of bed, or bending difficult.

\*Often overlaps with muscle, joint, or neuropathic pain, making it hard to isolate.

#### Management Considerations

\*Gentle stretching and range-of-motion exercises: Avoid overexertion but keep muscles flexible.

\*Heat therapy: Warm compresses or gentle heating pads can relieve stiffness.

\*Posture support: Ergonomic chairs, cushions, or neck supports help reduce strain.

\*Pacing and activity management: Avoid prolonged or sudden movements that worsen symptoms.

\*Medical guidance: In some cases, physical therapy tailored to ME may help strengthen supportive muscles.

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#### Key Features Across All Pain Types

\*Often disproportionate to exertion and worsens with post-exertional neuroimmune exhaustion (PENE).

\*Chronic, fluctuating, and multifactorial; multiple pain types may occur at once.

\*(Management: Pacing, gentle movement, rest, symptom-targeted therapies, and avoidance of triggers.

#### References

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Part 1 can be found here:

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