Several factors associated with long-term M.E. can contribute to bone loss over time:

Hormonal and autonomic dysfunction

ME-ICC discusses neurological, autonomic, endocrine, and immune dysfunction. Hormonal abnormalities involving cortisol, sex hormones, thyroid function, or autonomic regulation may indirectly affect bone health.

*Sunlight deprivation

Severe patients often spend years indoors with little sunlight exposure, increasing risk of vitamin D deficiency.

*Medication effects

Some medications sometimes used in chronic illness (especially steroids if ever prescribed) can accelerate bone loss.

*Menopause and aging

Age-related bone loss can occur alongside M.E., especially in women after menopause, making it important not to assume everything is “just M.E.”

Symptoms osteoporosis itself may not cause symptoms until:

*fractures occur

*height loss develops

*back pain from vertebral compression fractures appears

*posture changes occur

A doctor may evaluate this with:

*DEXA bone density scan

*vitamin D levels

*calcium and related bloodwork

*thyroid/parathyroid testing if needed

Things sometimes discussed with physicians for prevention/support include:

*safe weight-bearing activity within pacing limits

*vitamin D/calcium assessment

*nutrition support

*fall prevention

*osteoporosis medications when appropriate

One important point with ME-ICC: new or worsening symptoms should not automatically be attributed to M.E. alone. Conditions like osteoporosis, arthritis, nerve problems, vascular issues, or neurological disease can coexist and deserve proper evaluation.

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Management of low bone density (osteopenia or osteoporosis) in someone with long-term M.E. usually has to be adapted carefully to the person's energy limits and PEM threshold.

Common areas doctors may address include:

1. Bone Density Testing

*DEXA scan to measure bone density

*Repeat scans over time to monitor progression

2. Bloodwork / Underlying Causes

Doctors may check:

*Vitamin D

*Calcium

*Magnesium

*Phosphate

*Thyroid function

*Parathyroid hormone

*B12/folate

*Hormone levels when relevant

This helps identify treatable contributors to bone loss.

3. Nutrition

Adequate intake of:

*Calcium

*Vitamin D

*Protein

is important for bone maintenance.

Some people with severe M.E. struggle with:

*appetite

*food intolerances

*GI dysfunction

*inability to prepare meals

so management sometimes requires practical adaptations rather than “ideal” plans.

4. Movement Within Limits

For people with M.E., exercise advice must be individualized.

Traditional osteoporosis programs often emphasize weight-bearing exercise, but aggressive exercise can worsen M.E. through post-exertional Neuroimmune exhaustion (PENE).

Usually the safer approach is:

*avoid prolonged inactivity when possible

*use gentle tolerated movement

*remain within energy envelope/pacing limits

*prioritize preventing crashes

Even small amounts of carefully tolerated standing, shifting weight, or light resistance may help some patients — but this varies greatly by severity.

5. Fall Prevention

Especially important if:

*legs feel weak

*balance/proprioception is impaired

*orthostatic intolerance is present

*dizziness occurs

Helpful measures may include:

*mobility aids if needed

*reducing trip hazards

*shower chairs/grab bars

*sitting for tasks when possible

6. Medications

Doctors may prescribe osteoporosis medications depending on:

*age

*fracture history

*DEXA results

*overall risk

Examples include:

*bisphosphonates

*denosumab

*other bone-strengthening therapies

7. Vitamin D / Sunlight

Housebound or bedbound patients are at higher risk of vitamin D deficiency because of limited sunlight exposure.

Supplementation is often based on blood levels rather than guessing.

Important in M.E.

With ME-ICC, management often has to balance:

*preserving bone health

with

*avoiding PENE and functional deterioration

That means “push through and exercise more” is often not appropriate for many M.E. patients, especially moderate-to-severe cases.

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Treatment for osteopenia and osteoporosis aims to slow bone loss, improve bone strength, and reduce fracture risk. The approach depends on how low bone density is, age, sex hormones, fracture history, and overall risk.

Here are the main categories:

1. Lifestyle + foundational treatment (for both osteopenia and osteoporosis)

These are usually recommended first:

Nutrition

*Adequate calcium intake (from food or supplements if needed)

*Vitamin D (often supplemented, based on blood levels)

*Sufficient protein intake (important for bone matrix)

Lifestyle

*Avoid smoking

*Limit excess alcohol

*Maintain safe body weight (very low weight increases bone loss risk)

Fall prevention

*Home safety adjustments

*Vision checks

*Mobility aids if needed

*Address dizziness/orthostatic issues

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2. Medications for osteoporosis (or high fracture risk osteopenia)

Doctors choose based on risk level and medical history:

First-line (most common)

Bisphosphonates

*Examples: alendronate, risedronate, zoledronic acid

*Work by slowing bone breakdown

*Can be oral (weekly/monthly) or IV (yearly)

Other options

Denosumab (Prolia)

*Injection every 6 months

*Reduces bone resorption

*Needs ongoing administration (stopping suddenly can cause bone loss rebound)

Anabolic (bone-building) treatments

Used in higher-risk cases:

*Teriparatide (Forteo)

*Abaloparatide

*Romosozumab (where available)

These help build new bone, not just slow loss.

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3. Hormonal treatments (selected cases)

Depending on age and sex hormone status:

*Estrogen therapy (postmenopausal women in some cases)

*Testosterone therapy (if clinically low in men)

*Must be individualized due to risks and contraindications

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4. Treating underlying causes

If bone loss is driven by something else, that must be addressed:

*Vitamin D deficiency

*Thyroid overactivity

*Parathyroid disease

*Malabsorption (celiac, GI issues)

*Long-term steroid use

*Low body weight / undernutrition

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5. Exercise / mechanical loading (important but must be tailored)

Normally includes:

*Weight-bearing exercise

*Resistance training

In people with ME-ICC or severe fatigue conditions:

*Exercise must be carefully paced

*Avoid pushing into post-exertional worsening

*Focus on tolerable micro-movements rather than structured programs

Even small, safe loading (standing tolerance, gentle resistance bands, seated strength work) can be used if it does not worsen symptoms.

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6. Monitoring

*DEXA scans every 1–3 years (depending on risk)

*Blood tests for vitamin D and calcium balance

*Review of fracture risk (FRAX tool often used)

Key point

*Osteopenia = early warning

*Osteoporosis = higher fracture risk requiring stronger intervention

Treatment is usually a combination of medication + nutrition + fall prevention + safe mechanical loading, tailored to the individual's overall health and conditions like ME-ICC.

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Video approx 0:11:53

Osteoporosis

https://youtu.be/hzLGUM1hpUA?si=v3BGh0lAfRePWrtL

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