Persistent disequilibrium is a very real and under-recognized core symptom in Myalgic Encephalomyelitis (ME). It is not simple dizziness, and it is not anxiety. In ME, it reflects multisystem neuro-vascular and autonomic injury. Below is a clinically useful, ME-specific explanation.

What ‘persistent disequilibrium’ feels like in ME

Patients often describe:

* A constant off-balance / rocking / internal motion sensation

* Feeling pulled to one side, especially when upright

* Spatial disorientation without spinning (non-vertiginous)

* Worsening with standing, walking, head movement, visual complexity

* Marked aggravation with orthostatic stress or PENE

Importantly:

* Not episodic

* Not relieved by reassurance

* Often present even when sitting or lying

Core mechanisms in ME (not mutually exclusive)

1. Cerebral hypoperfusion (especially posterior circulation)

Well-documented in ME:

* Reduced cerebral blood flow when upright

* Inadequate perfusion to: Cerebellum; Vextibular Nuclei; Parietal spatial-orientation cortex. Result: constant balance mismatch, not spinning vertigo

This explains:

* Worsening when upright

* Improvement when lying flat

* Association with headache, visual distortion, cognitive fog

2. Autonomic failure (OCHOS, POTS, low stroke volume)

ME patients frequently have:

* Impaired baroreflex

* Reduced preload

* Inadequate cardiac output on standing

Even without classic POTS:

* Subtle autonomic instability can cause continuous disequilibrium

The brain never receives consistent perfusion signals leading to chronic imbalance

3. Central vestibular dysfunction

Unlike BPPV or inner ear disease:

* ME involves central vestibular processing

* Poor integration between: vestibular input; visual input; proprioception

This causes:

* Visual motion intolerance

* “Walking on a boat” sensation

* Difficulty in busy environments

Vestibular tests may appear “normal” at rest

4. Neuroinflammation & glial activation

Evidence in ME shows:

* Activated microglia

* Cytokine-mediated signaling dysfunction

Affected regions include:

* Brainstem

* Cerebellum

* Thalamus

Leads to persistent sensory miscalibration, not episodic vertigo

5. Energy failure in balance pathways

Balance is energy-intensive.

In ME:

* Mitochondrial dysfunction

* Impaired oxygen extraction

* Poor lactate clearance

Disequilibrium worsens with:

* PENE

* Infection

* Poor sleep

* Overexertion

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How this differs from other causes

* Not BPPV - no brief spinning with position change

* Not Ménière's - no fluctuating hearing loss

* Not anxiety - persists during calm, rest, and sleep-wake transitions

* Not deconditioning - present even early in illness

Red flags that support ME-related disequilibrium

* Improves when supine

* Worsens with orthostatic stress

* Accompanied by: head pressure; visual distortion; cognitive slowing;

* Resistant to standard vestibular rehab

Practical management (ME-appropriate)

Foundational

* Strict orthostatic pacing

* Supine rest breaks

* Avoid prolonged standing or visual overload

Circulatory support

* Adequate fluids and salt (if tolerated)

* Compression garments (abdomen > legs)

* Head-of-bed elevation at night

Environmental adaptations

* Minimize visual motion

* Stable lighting

* Avoid scrolling while upright

Vestibular rehab — with caution

* Only very gentle, ME-aware protocols

* Stop well before symptom escalation

* PENE safe approach is essential

Medications (case-by-case)

* Low-dose beta-blockers, ivabradine, or fludrocortisone only if autonomic dysfunction confirmed

* Migraine preventives may help central vestibular processing

* Avoid aggressive vestibular suppressants long-term

Why this matters clinically

Persistent disequilibrium in ME:

* Signals ongoing cerebral hypoperfusion

* Increases fall risk

* Drives cognitive overload

* Is a marker of disease severity, not a minor symptom

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Practical, ME-appropriate management plan for persistent disequilibrium, focused on stabilising physiology firstand avoiding PENE. This is written the way I'd want a clinician or carer to understand it.

CORE principle (most important)

Do not train balance on an unstable system. In ME, disequilibrium usually reflects cerebral hypoperfusion + autonomic failure + neuroimmune dysfunction. Pushing vestibular rehab too early worsens symptoms and triggers PENE.

Postural & Pacing Management

Upright exposure

* Break standing into seconds–minutes, not tasks

* Sit for tasks whenever possible

* Avoid standing still (worse than slow walking)

Supine resets

* Scheduled flat rest during the day (not just when “crashing”)

* Head neutral, eyes closed or low-stimulus

Morning strategy

* Delay upright activity after waking

* Fluids before standing

* Avoid showers early in the day if possible

Circulatory

(Only what is tolerated — ME patients vary)

Fluids & volume

* Small, frequent fluid intake

* Salt supplementation if BP allows

* Avoid large fluid boluses that worsen nausea

Compression

* Abdominal compression is more effective than legs

* Waist-high if tolerated

* Use during upright tasks only

Thermal control

* Avoid heat

* Cooling vest or cool packs for head/neck if flushing worsens disequilibrium

Visual & Sensory Load reduction

Disequilibrium worsens with sensory mismatch.

Vision

* Reduce scrolling while upright

* Large font, low contrast glare

* Limit busy visual environments

Sound & motion

* Avoid multitasking

* One sensory input at a time

* Sunglasses indoors if light triggers imbalance (not full darkness)

Vestibular Rehabilitation-only if stable

This is NOT standard vestibular physio.

When to consider

* Only after orthostatic symptoms are reasonably controlled

* No recent PENE flares

* Baseline stable for weeks, not days

How to do it safely

* Supine or seated exercises only

* Very short exposure (seconds)

* Stop before symptoms rise, not after

* No gaze stabilization drills while upright initially

Avoid:

* Balance boards

* Walking drills

* Head-turning while standing

* “Push through” protocols

Cervical & Postural Support

Upper cervical dysfunction can worsen disequilibrium.

* Neutral neck positioning

* Avoid sustained neck flexion

* Gentle isometric support (not stretching)

* Trial soft cervical support if head feels “heavy”

Medication Considerations (case by case)

These are supportive, not curative.

Autonomic support

* Low-dose beta-blocker or ivabradine (if tachycardia predominant)

* Fludrocortisone or midodrine only if hypotension documented

Central processing

* Migraine preventives (e.g., low-dose amitriptyline, topiramate) if migrainous features

* Avoid long-term vestibular suppressants (e.g., meclizine)

Sleep & inflammation

* Prioritize sleep stability

* Address infections or immune flares promptly

Red Flags - reassess strategy

If any of the following worsen:

* Disequilibrium becomes continuous even supine

* New focal neurological symptoms

* Increasing head pressure or vision loss

* Falls or near-syncope

Re-evaluate for:

* Worsening hypoperfusion

* Cervical instability

* CSF pressure disorders

How to explain this to a Dr.

“My balance problems aren’t spinning vertigo. They’re constant, worse when I’m upright, and better lying down. Standard vertigo treatments have made me worse, which fits with my ME. I’m hoping we can look at circulation or autonomic causes instead.”

References

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