Remissions in Myalgic Encephalomyelitis

1. “Remission” in ME is rarely a true recovery

In classical ME cohorts (Ramsay, Hyde, Richardson), remission usually meant a temporary improvement of functional capacity, not a return to premorbid physiological normalcy.

*Patients may regain partial activity tolerance.

*Underlying abnormalities—immune activation, autonomic instability, and viral persistence—are generally still present.

*Because the disease mechanism remains active, the remission is unstable and prone to relapse with relatively minor triggers.

2. What often improves during remission

Remission phases often reflect a downshift in ongoing CNS and autonomic injury, not resolution of it. Many report:

*Reduced orthostatic intolerance

*Slightly improved cognitive stamina

*Decreased myalgia and neuropathic pain

*Fewer episodes of acute-like systemic symptoms (flu-like waves, chills, sore throat, lymph node pain)

*Improved tolerance to light, sound, and sensory load

*Calmer cardiometabolic state (fewer adrenaline surges, less tachycardia)

But these improvements remain fragile.

3. What does not resolve, even in remission

Biomedical findings consistently show that the underlying disease markers remain abnormal:

*Impaired oxygen extraction and abnormal cardiopulmonary response on repeat CPET

*Persistently low circulating blood volume

*Autonomic dysfunction (especially parasympathetic withdrawal)

*Residual neuroinflammation on PET/SPECT

*Immunological dysregulation (low NK function, abnormal RNase L profile in some cohorts)

*Enteroviral persistence when present at onset. Thus, remission is not biologic healing, but rather a window of reduced stress on compromised systems.

4. What typically causes a remission?

Often spontaneous and not linked to treatment. Documented triggers include:

*Reduction of physiological stressors (infection load, inflammation, temperature extremes)

*Correction of a secondary issue (e.g., iron deficiency, thyroid imbalance, vitamin B12 deficiency, or untreated sleep apnea)

*Periods of enforced rest

*More stable autonomic environment (consistent hydration, salt, compression, temperature control)

*Natural oscillation of disease activity

Remissions do not usually result from graded exercise, psychological intervention, or “mind-body” techniques.

5. What commonly ends a remission?

Relapse triggers are well described:

*Minor viral infection

*Vaccinations in some individuals

*Temperature extremes

*Anaesthetic or surgical stress

*Emotional or physiological stress

*Overexertion (especially cognitive or orthostatic)

*Travel

*Hormonal changes

*Sleep disruption. Relapses often return the patient to their baseline disease severity or worse.

6. Rare complete remissions (“near-recovery”)

A small subset of patients—often early in the disease—experience a period that resembles recovery, sometimes lasting months or years. But:

*They remain physiologically vulnerable.

*Most eventually relapse after infection, exertion, or major stress.

*In Dr. Hyde's longitudinal cohorts, true permanent recovery was extremely rare, and only seen in individuals diagnosed and rested early, before major CNS injury accumulated.

7. Remissions across severity levels

Mild ME:

*Most likely to experience multi-month remissions.

*May temporarily function near normal with strict pacing.

*Still unable to sustain exertion without PENE

Moderate ME:

*Remissions allow limited return to part-time function or increased independence.

*PENE threshold remains low.

Severe ME:

*Remissions may mean tolerating light better, fewer neurological storms, or being able to sit up briefly.

*Function remains profoundly restricted.

Very severe ME:

*Remission generally means stabilization rather than functional improvement (e.g., pain slightly reduced, less constant adrenaline surge, fewer episodes of autonomic collapse).

*Capacity remains extremely limited.

8. The psychological impact of remission

Many experience:

*Fear of losing the improvement

*Pressure from others to "return to normal"

*Grief when relapse occurs

*Confusion about managing activity levels

*Emotional whiplash: hope - fragility - setback - fear.

Education about the instability of remission is protective.

References

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