ME is devastating at every level. Mild, moderate, and moderate-severe ME can completely dismantle a person's life, their careers, finances, relationships, identity. No one here is "lucky" to have ME. That said, it's important to understand that severe and very severe ME exist on an entirely different physiological and functional plane.

Severe and Very Severe ME is not simply "worse fatigue" or "more symptoms." It is a state of profound neurological and systemic failure in which a person may be:

* Mostly Bedbound.

* Unable to tolerate light, sound, smell, touch, or conversation

* Unable to sit up, speak, eat normally, or think clearly

* Dependent on others for basic survival

* At risk of dehydration, malnutrition, and medical neglect

Recognizing severe ME does not minimize anyone else's suffering. Instead, it:

* Helps us understand the full spectrum of this disease

* Explains why early pacing and protection matter so much

* Prevents harmful comparisons and expectations

* Centers those who are too sick to advocate for themselves

If your ME is already unbearable, please know: severe ME goes far beyond what most people ever encounter.

Does M.E. start out Severe or do people become severe?

Both happen.

A. Some people are severe from the start

A subset of patients become severe or very severe at onset, especially after:

* A sudden viral or post-infectious illness

* Severe neurological involvement early on

* Lack of early rest and enforced exertion during the acute phase

In these cases, people may go from "previously healthy" to bedbound or housebound within weeks or months.

This is well-documented, but often ignored in clinical narratives.

B. Many people progress from mild/moderate to severe

More commonly, people:

*Start mild or moderate

*Are misdiagnosed or told to push through

*Are exposed to: Graded exercise; Return-to-work/school pressure; Repeated PENE crashes.

*Gradually or suddenly, they decline into severe or very severe ME

This progression is not inevitable, but it is common when exertion exceeds physiological limits. Severe ME is often caused or worsened by repeated overexertion, not by "deconditioning."

What defines mild, moderate and severe M.E.?

Severity in ME is defined by functional capacity, not symptoms alone.

Mild M.E.

Functional level

* Mobile and self-caring

* Can leave the house

* Often able to work or study part-time or with accommodations

Key features

* PENE occurs but recovery is shorter

* Can tolerate limited social and cognitive activity

* Often misunderstood as "fatigue" or stress

Risk

* High risk of deterioration if pushed or mismanaged

Moderate M.E.

Functional level

* Mostly housebound

* Cannot work or attend school

* Requires frequent rest

* Basic daily activities are difficult

Key features

* PENE is reliable, delayed, and prolonged

* Cognitive dysfunction is obvious

* Autonomic symptoms interfere with daily life

Transition risk

* This is where many patients become severe if pacing is not strict

Severe M.E.

Functional level

* Mostly bedbound

* Requires assistance with basic care

* Very limited tolerance for: Light, Sound, Smell, Touch, Conversation, Cognitive effort

Key features

* PENE triggered by minimal exertion

* Marked neurological dysfunction

* Severe autonomic instability

* Muscle weakness that can resemble paralysis

* Difficulty speaking or processing language

* Eating, swallowing, and digestion may be impaired

Severe ME is not just “more fatigue” - it is a distinct level of neurological and systemic dysfunction.

Very Severe ME

Functional level

* Completely bedbound

* Often unable to: Speak; Eat independently; Tolerate light, sound, or touch

Key features

* Extreme sensory hypersensitivity

* Profound energy failure

* Minimal interaction with the environment

* High risk of: Malnutrition; Dehydration; Pressure injuries; Medical neglect

Many very severe patients are invisible to healthcare systems.

A critical advocacy point

Severe ME is not rare, and it is not caused by psychological factors.

It reflects:

* Profound neurological dysfunction

* Cellular energy failure

* Autonomic and immune dysregulation

Many severe patients could have remained mild or moderate with:

* Early recognition

* Strict rest

* Protection from forced exertion

Pictures are from the ICPrimer 2012 - a diagnostic tool for the International Consensus Criteria. https://investinme.org/…/Myalgic%20Encephalomyelitis…

https://www.dialogues-mecfs.co.uk/films/severeme/

https://www.mdpi.com/2227-9032/9/2/215

https://25megroup.org/resources/carers-guidance-resources/

#GAME

#NightingaleContinuum