ME/CFS Quick-Start for Clinicians (10–15 min)

ME/CFS is a chronic, disabling, multisystem disease marked by Post-Exertional Malaise (PEM), unrefreshing sleep, cognitive dysfunction, and often orthostatic intolerance (OI). The goal of a first visit is to validate, identify PEM/OI, rule out common mimics, begin symptom-directed care, and set a safe follow-up plan.

Key Principles

- Validate and name PEM; avoid recommending graded exertion that provokes crashes.
- Assume energy limits: use pacing/‘energy-envelope’ framing from day one.
- Screen for OI with lying’standing vitals and symptom history.
- Start with low-risk symptom relief while ruling out mimics; escalate thoughtfully.

What Not to Do

- Avoid dismissing symptoms as purely psychological when PEM/OI features are present.
- Do not push patients to ‘build stamina’ through fixed-increment exercise when PEM is present.
- Do not use Graded Exercise Therapy (GET) or fixed-progression activity plans; these can trigger or worsen PEM.
- Do not present Cognitive Behavioral Therapy (CBT) as disease-modifying; at most, offer it as optional coping support.
- Avoid large medication changes during an acute crash; go ‘start low, go slow’.

First Visit Flow

- History highlights: exertion triggers/delays (24–48 h), sleep quality, brain fog, upright symptoms.
- PEM screen: “Do your symptoms worsen after small efforts, often with a 24–48 h delay?”
- OI screen: lightheadedness/palpitations/‘pressure’ upright; intolerance of heat/showers/standing.
- Lying’standing vitals at 0, 2, 5, 10 min; document HR/BP + symptoms.
- Baseline tests & differentials (see Workup).
- Initial plan: pacing education; fluids/salt/compression if OI suspected; sleep and pain support.
- Follow-up timeframe: 4–6 weeks with a written crash-prevention plan.

Post-Exertional Malaise (PEM)

Post-Exertional Malaise (PEM) is a hallmark: a delayed (often 24–48 h) worsening of symptoms after minor physical, cognitive, or orthostatic stress. It is characterized by flu-like symptoms, including muscle aches and soreness, general malaise, a 'poison' like feeling throughout the body, extreme fatigue, chills and other symptoms. Management prioritizes preventing PEM via pacing, activity modification, and symptom-guided titration.

Orthostatic Intolerance Screen

- Supine rest 10 min ’ record HR/BP.
- Stand unsupported; record HR/BP at 2, 5, 10 min and track symptoms.
- First-line: ~2–3 L fluids/day as tolerated, liberalize salt if safe, waist-high compression.
- Consider meds when conservative measures insufficient and clinically appropriate (e.g., fludrocortisone, midodrine, beta-blocker, pyridostigmine).

Baseline Workup

- CBC, CMP, TSH/Free T4.
- Ferritin/iron studies, B12, folate, vitamin D.
- CRP/ESR; ANA if autoimmune features.
- HbA1c, lipids as indicated.
- Morning cortisol if adrenal concern.
- Sleep evaluation if symptoms suggest OSA/PLMD.

- Orthostatic testing (lying/standing; consider tilt when appropriate).
- Additional tests driven by history/exam.

Initial Management

- Pacing/energy envelope education; activity should not provoke PEM.
- Sleep: hygiene; consider melatonin or low-dose agents for restorative sleep.
- Pain/headache: multimodal; treat migraine where present.
- OI: fluids/salt/compression ± medications per judgment and comorbidities.
- Correct deficiencies (vitamin D, B12, iron/ferritin).
- Consider low-dose naltrexone (LDN) via shared decision-making for pain/fatigue modulation.

Follow-Up

- Schedule in 4–6 weeks; review PEM frequency/severity and OI symptoms.
- Titrate measures based on response; avoid changes that trigger crashes.
- Provide written pacing guidance and crash plan; involve caregivers when helpful.

Red Flags

- Red, hot, or swollen joints; true focal neurologic deficits; chest pain/syncope without warning.
- Rapid unintentional weight loss, fevers, drenching night sweats.
- Severe depression, suicidality, unsafe home environment.

Documentation Templates

Assessment

Chronic multisystem illness consistent with ME/CFS. Hallmark Post-Exertional Malaise (PEM) present. Symptoms include unrefreshing sleep, cognitive dysfunction, and orthostatic intolerance. Exam notable for [findings]. Lying’standing vitals show [results].

Plan

Education re: PEM and pacing; avoid exertion that provokes crashes. OI measures: fluids/salt/compression; consider [med] if conservative measures insufficient. Sleep optimization: [intervention]. Address pain/headache per multimodal plan. Labs ordered for differentials. Follow-up 4–6 weeks.

Accommodations

Recommend flexible scheduling, remote options, reduced continuous upright time, quiet spaces, and rest breaks to prevent PEM; provide note as needed.