

Managing Specific Symptoms of ME/CFS: Orthostatic Intolerance, Sleep Problems, Pain, and Memory/Concentration Problems

Effective medications and strategies DO exist to alleviate the symptoms of ME/CFS and treat comorbid conditions.



ORTHOSTATIC INTOLERANCE (OI)

Patients with symptoms of OI should receive further evaluation, including in-office orthostatic testing and, in some cases, referral for formal tilt table testing. Since many OI symptoms (e.g., racing heart rate, feeling lightheaded) are similar to those seen in an anxiety disorder, patients with previous anxiety diagnoses should be carefully re-evaluated.

Initial treatments include:

- Blood volume expansion for those patients with ME/CFS who do not have heart or blood vessel disease
- Behavioral measures such as lying down, sitting cross-legged while in a chair, or placing feet on the floor
- Sitting in the shower
- Keeping cool in hot weather
- Compressional stockings or other garments

If symptoms do not improve with these steps, medications can be prescribed. It may be helpful to refer patients to a cardiologist and/or neurologist with experience treating autonomic issues.



SLEEP PROBLEMS

Patients' sleep problems may be related to an excess of sympathetic nervous activity and HPA-axis dysregulation or nocturnal pain. Therefore, while actions promoting good sleep hygiene should be tried and maintained, patients may continue to experience problems getting to sleep, staying asleep, or waking up unrefreshed. Initially, over-the-counter sleep products might be indicated. If this does not help, sleep medicine can be prescribed starting at the smallest dose. Patients should be educated about sleep medication side effects and warned about interactions with alcohol, herbs, supplements, and other substances. Referral to a sleep specialist may be helpful.

Note that not all sleep hygiene practice (e.g., bed only for sleep, no computers in bed, no daytime napping) will be appropriate for patients who are severely ill and bedbound or who have OI and spend their days lying flat.



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PAIN

Headaches, muscle pain, and noninflammatory multi-joint pain are common in patients with ME/CFS. However, healthcare providers should evaluate pain in patients thoroughly before attributing it to ME/CFS. For example, migraine headaches, fibromyalgia, and temporomandibular joint disorder can co-exist with ME/CFS and have specific therapies.

- For nonspecific, intermittent, or mild pain, over-the-counter, as-needed pain relievers (like acetaminophen, aspirin, or ibuprofen) can be considered first. Their use should be monitored for safety and efficacy.
- Other nonpharmacological pain management methods can also be beneficial for individual patients, including stretching and movement therapies, gentle massage, heat, toning exercises, and hydrotherapy.
- While methods that involve physical activity such as stretching might be helpful, initiating or resuming stretching and movement therapies requires careful consideration to avoid post-exertional malaise (PEM).
- Acupuncture, when done by a licensed practitioner, might help with pain for some patients.
- Some patients use earplugs, eye masks, face masks, and mobility devices to minimize PEM and sensory sensitivities.

If these therapies do not provide enough pain relief, evaluation by a pain specialist may be indicated. As for any patient with chronic pain regardless of etiology, counseling for pain management techniques is also advisable and can be helpful.



MEMORY AND CONCENTRATION PROBLEMS

Memory problems might be managed to some extent by using memory aids such as organizers, notebooks, or recording devices. Electronic devices, such as smart phones and tablets, can store information and set reminders for medications and appointments. A quiet, calm environment and avoidance of multitasking may help with concentration. Since slowed information processing speed underlies many of the cognitive issues in ME/CFS, an effective technique is planning more than adequate time to complete a cognitive task with multiple intermittent breaks.

Mild prescription stimulants may help some patients with overall fatigue, cognitive symptoms, and OI. However, stronger stimulants can lead to a flare-up as patients may attempt to do too much when they feel better. This can lead to the “push-crash cycle:” do too much, crash, rest, start to feel a little better, do too much once again, and so on. Keep in mind that patients may develop dependence and tolerance to stimulants over time and that any withdrawal must be done under careful supervision.

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**For more information on ME/CFS,
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