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The Critical Need for Home Collection Services for Patients with Severe-Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Overview

This document provides essential clinical context regarding patients with severe to very severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) to support requests for home-based phlebotomy and pathology collection services.

ME/CFS is a long-term, complex, multi-systemic and debilitating condition that affects the immune, nervous, endocrine, and autonomic systems.[1] It's a condition where the body struggles to produce enough energy for normal functioning.[2] If a patient overexerts themselves within a 24-hour period, exceeding the limited energy their cells generate, they experience the defining symptom of ME/CFS: Post-Exertional Malaise (PEM), often referred to as a "crash." The body simply can't replenish this energy deficit fast enough.[3]

In 2015, the Institute of Medicine (IOM) proposed a name change to "Systemic Exertion Intolerance Disease" (SEID) to better reflect the illness's nature, highlighting that problems arise from any form of exertion, not just physical exercise.[4] The illness's severity can fluctuate significantly. Patients might occasionally handle slightly more exertion, while at other times they can do even less than usual. Therefore, activity levels must always be determined by their current level of severity.

While laboratory funding criteria for home visits are necessarily specific, often focusing on patients who are bedridden, it is crucial to understand that many patients with severe to very severe ME/CFS meet this criteria due to the pathophysiology of their illness. The unique nature of this condition means that the effort of attending an outpatient appointment is impossible and/or poses a significant medical risk, making a home visit absolutely necessary. The phlebotomist also needs to consider that the patients may not be able to tolerate sound, light, or the smell of

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[1] Grach, S.L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome. *Mayo Clinic Proceedings, 98*(10), 1544-1551. Link.

[2] https://ammes.org/tag/impaired-muscle-energy-metabolism/

[3] ME/CFS Basics | ME/CFS | CDC https://share.google/453C6uRK5X4EQgqlO

[4] MECFS_ReportBrief.pdf https://share.google/kmvBTYEiDEQMkZ4wf

perfumes or strong smelling products. Furthermore, they may also have allergies or intolerances to certain agents to cleanse the skin.[5]

Understanding Severe and Very Severe ME/CFS

Patients with severe to very severe ME/CFS are often housebound and/or bedbound. **People with severe ME/CFS, estimated as 25% of those affected, have been defined as being almost exclusively housebound and unable to attend healthcare consultations, and often bedbound all or some of the time.**[6] Their functional capacity is extremely limited, and they exist in a state of profound exhaustion that is not alleviated by rest.

Those with severe to very severe ME/CFS experience a profound loss of their pre-illness function. These patients are defined by the following limitations:

- **Severe ME/CFS:** Patients are mostly housebound and predominantly bedbound, and require wheelchair assistance for mobility. Their daily life is limited to minimal hygiene activities. Just doing something as basic as walking to the toilet can leave them exhausted and bedbound for the rest of the day or week. They may struggle to speak, tolerate human presence, or process sensory input like strong odours or perfumes, light, sound, or touch.
- **Very Severe ME/CFS:** Patients are 100% bedridden, require 24/7 care and cannot do anything independently. They struggle to speak, tolerate human presence, or process sensory input like strong odours or perfumes, light, sound, or touch. Any interaction, exertion, or sensory stimuli can result in Post-Exertional Malaise.

The key symptom of ME/CFS is Post-Exertional Malaise (PEM).

Post-Exertional Malaise (PEM) is a severe worsening of all symptoms after even minimal physical, mental, or sensory exertion. **It is debilitating and increases the individual's dependency on others.**[7] The onset of PEM is often delayed by 24 - 48 hours and can last for days, weeks, or even months. The exertion required to trigger PEM can be as minor as sitting upright, a short conversation, or being transported in a vehicle. This is not simply “tiredness” - it is a debilitating response to everyday activities that were previously manageable.[8]

For a patient with severe ME/CFS, the act of preparing for, traveling to, and attending a laboratory appointment constitutes a significant exertion that can lead to a severe relapse, causing:

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[5] Maeda, K. I., Islam, M. F., Conroy, K. E., & Jason, L. (2023). Health outcomes of sensory hypersensitivities in myalgic encephalomyelitis/chronic fatigue syndrome and multiple sclerosis. *Psychology, health & medicine*, *28*(10), 3052–3063. DOI.

[6] Kingdon, C., Giotas, D., Nacul, L., & Lacerda, E. (2020). Health Care Responsibility and Compassion—Visiting the Housebound Patient Severely Affected by ME/CFS. *Healthcare*, *8*(3), 197. https://doi.org/10.3390/healthcare8030197

[7] Same as above

[8] Friedberg, F., Bateman, L., Bested, A.C., Davenport, T., Friedman, K.J., Gurwitt, A., Jason, L.A., Lapp, C.W., Stevens, S.R., Underhill, R.A., Vallings, R. (2014). Chronic fatigue syndrome myalgic encephalomyelitis: Primer for clinical practitioners 2014 edition. International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME.

- **Increased pain:** Widespread muscle and joint pain (myalgia and arthralgia).
    - Muscle pain is experienced by 96% of people with severe ME/CFS, with half reporting it as severe.[9]
- **Neurological disturbances:** Worsening of cognitive dysfunction ("brain fog"), headaches, and an inability to process information.
    - A significant majority of severe ME/CFS patients struggle with cognitive functions: for instance, 96% have difficulty finding words and concentration problems, and 95% report brain fog and short-term memory issues. [10]
- **Autonomic dysfunction:** Dizziness, palpitations, and blood pressure instability (orthostatic intolerance).
    - Intolerance to standing is experienced by 81% of people with severe ME/CFS, with 50% reporting it as severe.[11]
- **Profound fatigue:** A level of exhaustion that can lead to muscle weakness and, in some cases, paralysis.
    - Disabling fatigue affects 100% of severe ME/CFS patients and is universally reported as severe. Unrefreshing sleep is experienced by all, and sleep problems affect 83% of patients.[12]
- **Sensory overload:** Severe sensitivity to light, sound, odours, touch, and/or movement.
    - 91% experience unusual sensitivity to light and/or noise (45% severe), and 88% develop new sensitivities to food, medication, chemicals or odours (43% severe).[13]

Because many health services don't offer home visits, many patients with ME/CFS simply choose to forgo appointments for health screenings, optometrists, dentists, and other services.[14] Alternatively, they might select one essential visit, meticulously plan for it by doing even less than usual beforehand, and then brace for the inevitable worsening of their health and fatigue. This could mean they can only attend one important appointment a month, or even a year, or none at all, often causing them to fall through the cracks in the health system.

Why Apparent Health or Mobility is Deceiving

A patient with severe ME/CFS might be able to move with assistance, or even move to a different room or be wheeled to or walk to the toilet, but this does not mean they can safely attend an appointment. ME/CFS is a multi-systemic condition - it is not an illness that is necessarily visible on the outside. If a patient manages their energy carefully they can appear quite well, as long as they do very little. It is important to understand that a patient may use all their limited energy

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[9] Same as above

[10] Kingdon, C., Giotas, D., Nacul, L., & Lacerda, E. (2020). Health Care Responsibility and Compassion—Visiting the Housebound Patient Severely Affected by ME/CFS. *Healthcare*, *8*(3), 197. https://doi.org/10.3390/healthcare8030197

[11] As above

[12] As above

[13] As above

[14] Montoya, J. G., Dowell, T. G., Mooney, A. E., Dimmock, M. E., & Chu, L. (2021). Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Healthcare (Basel, Switzerland)*, *9*(10), 1331. https://doi.org/10.3390/healthcare9101331 https://pmc.ncbi.nlm.nih.go#v/articles/PMC8544443/

reserves to manage a brief interaction, giving a misleading impression of their health. Others may seem animated and engaged, making it difficult for the practitioner to recognise the extent of their illness.[15]

The environment of a waiting room and collection centre can be intensely overwhelming and painful for a patient. The noise, the light and the smells trigger sensory overload. The very act of moving or sitting upright can be more than enough exertion to trigger a severe PEM relapse. The subsequent "crash" is invisible to an observer but has devastating consequences for the patient often setting their baseline health back for days, weeks, or even months.

Clinical Justification for Home Visits

For patients, both with severe or very severe ME/CFS, a home visit is not a matter of convenience, it is a vital component of medical care required to prevent medically-induced harm. **Many Severe ME cases lie at home without having seen a doctor for many years. Case studies have demonstrated there is benefit from ongoing home visits received by patients, for both moral support and symptomatic treatment.**[16] Forcing these patients to attend a collection centre can lead to a significant and prolonged deterioration in their condition.

Therefore, when a home visit is requested for a patient with a diagnosis of severe or very severe ME/CFS, we ask that you consider this information as the detailed clinical justification. The request is made on the grounds that the patient is unable to attend an appointment for clear medical reasons directly related to the pathophysiology of their disease.

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[15] As above

[16] Speight, N. (2020, July 14). Severe ME in Children. *Healthcare (Basel)*, *8*(3), 211. https://pmc.ncbi.nlm.nih.gov/articles/PMC7551866/