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The Critical Need for Domiciliary Care by Health Professionals 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 Domiciliary Services from Health Professionals.

ME/CFS is a long-term, complex, multi-systemic and debilitating condition that affects the nervous, endocrine, autonomic, cardiovascular, and immune systems. It's a condition where the body struggles to produce enough energy for normal functioning. 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.[1] This is not something that any other illness presents with - it's a unique feature of ME/CFS. In other illnesses the body recovers quickly after rest, but not in those with ME/CFS.

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.[2] 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 **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. Health Professionals also need to consider that the patients may not be able to tolerate sound, light, or the smell of perfumes' or

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[1] ME/CFS Basics | ME/CFS | CDC https://share.google/453C6uRK5X4EQqgIO

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

strong smelling products such as medications or certain topical wipes used to cleanse the skin before administering injections .

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.**[3] 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.

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.**[4] 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.

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

- **Increased pain:** Widespread muscle and joint pain (myalgia and arthralgia).

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[3] 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

[4] 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

    - **Muscle pain is experienced by 96% of people with severe ME/CFS, with half reporting it as severe.**[5]
- **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.** [6]
- **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.**[7]
- **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.**[8]
- **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).**[9]

Patients 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 in Severe and Very Severe ME/CFS

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 reserves to manage a brief interaction, giving a misleading impression of their health. Others

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[5] 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

[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] 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

[8] 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

[9] 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

may seem animated and engaged while interacting, making it difficult for the practitioner to recognise the extent of their illness - not seeing the 'crash' that follows as a result of PEM.[10]

The environment of a waiting room in A & E or the hospital 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

Because many health services don't offer home visits, **many people with severe ME/CFS commonly receive no care from healthcare professionals, while some have become distanced from all statutory medical services. It is often the most seriously ill who are the most neglected by those responsible for their healthcare.**[11] **Sadly, many patients and their caregivers have reported experiencing neglect or poor treatment from previous medical providers. As a result, they've often had to become their own experts.**[12]

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. **Case studies have demonstrated there is benefit from ongoing home visits received by patients, for both moral support and symptomatic treatment.**[13] Forcing patients to attend a **medical appointment** can lead to a significant and prolonged deterioration in their condition.

- **Healthcare Professionals are duty-bound to ensure that the person with severe ME/CFS receives the person-centred care she/he needs.**[14]
- **Compassion and responsibility should guide all interactions between healthcare professionals and patients, particularly important when interacting with people with severe ME/CFS.**[15]

In summary, 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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[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] 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

[12] 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.go1v/articles/PMC8544443/

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

[14] 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

[15] 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