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RE: Feedback on CDC Long COVID Patient Materials

The Myalgic Encephalomyelitis Action Network (#MEAction) writes to provide the CDC with feedback on potential materials they are developing to assist Long COVID patients when seeking care.

Some Long COVID patients will meet the criteria for ME/CFS, and when they do, they need to be recognized as having ME/CFS so they can receive appropriate help. There are specific testing and treatment protocols to help people living with ME/CFS or those who are experiencing ME/CFS-related symptoms who have yet to be diagnosed.

Patients with ME/CFS symptoms - distinctive symptoms such as post-exertional malaise (PEM), as well as unrefreshing sleep, cognitive impairment, and orthostatic intolerance - need to:

1. be aware these symptoms exist,
2. have an accurate, plain-English description of the symptoms,
3. receive information on appropriate treatments / management strategies for the symptoms (e.g., pacing, staying within one's energy envelope, managing orthostatic intolerance), and
4. be warned about inappropriate treatments that could exacerbate their symptoms (e.g., exercise therapy).

ME/CFS often goes undiagnosed by healthcare providers who may not have accurate information about recognizing, diagnosing, and treating ME/CFS. It is essential that CDC give Long COVID patients as much information about diagnosing and treating ME/CFS as possible so they can have effective conversations with their healthcare providers and prevent risk of further harm.

RECOMMENDATIONS

1. Long COVID patients need more than a list of symptoms that overlap with ME/CFS. CDC materials on Long COVID need to include links to CDC's ME/CFS materials on criteria for ME/CFS diagnosis so patients can discuss whether a diagnosis is indicated with their healthcare provider.
2. PEM is a distinctive symptom for which standard exercise therapies are not appropriate. Patient materials should describe the symptom and give patients information on both what they should and shouldn't do for treatment. This information can be found in the

CDC's ME/CFS healthcare provider toolkit, and should be made more accessible to Long COVID patients (e.g., [What Are ME/CFS Symptoms?](#), [Managing Post-Exertional Malaise \(PEM\) in ME/CFS](#), [Managing Specific Sx of ME/CFS: Orthostatic Intolerance, Sleep Problems, Pain, and Memory/Concentration Problems](#)).

3. CDC Long COVID patient materials should link to the U.S. ME/CFS Clinician Coalition [Handout on Diagnosing and Treating ME/CFS](#) and [Treatment Recommendations](#). The CDC website already contains a link to the Clinician Coalition website in the "Resources" section of the [Healthcare providers](#) page. Because there are so few ME/CFS clinician specialists, the CDC needs to robustly equip Long COVID patients with suspected ME/CFS to have informed conversations with their healthcare providers.
4. Long COVID material on ME/CFS - for patients and healthcare professionals - should clearly state that ME/CFS can affect children and adolescents, as well as adults.

Sincerely,

Ben HsuBorger
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#MEAction

CC:
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