



**PATIENT-LED
RESEARCH
COLLABORATIVE**

Long COVID and Associated Conditions¹ Policy Recommendations for the Department of Labor

Sourced from people with Long COVID and ME/CFS from [#MEAction](#), [Body Politic](#) & [Patient-Led Research Collaborative](#). For questions, reach out to Ben HsuBorger at ben@meaction.net

Key Issues

- **Lack of benefits for newly disabled:** People with Long COVID and Associated Conditions (LCAC) are being denied disability benefits of all types, particularly employer-sponsored long-term disability, short-term disability.
- **Lack of benefits for long-time disabled:** Disability insurance providers are increasingly denying long-standing active claims of those who were disabled before COVID-19.
- **Mental/Nervous misclassification:** Insurance companies are frequently misclassifying LCAC as mental/nervous, which limits lifelong benefits to 2 years. Medical record references to secondary anxiety or depression resulting from the primary complex, post-infectious condition are seized upon to limit benefits, as are “subjective” patient-reported symptoms.
- **Lack of reporting:** LCAC prevalence and its impacts on work are not being tracked, which makes it difficult for the government and employers to adequately respond to the crisis.
- **Lack of awareness.** Many employers and workers are not familiar with LCAC, and do not know how to manage symptoms and what accommodations can help keep them working.

Policy Recommendations

1. The [Office of Disability Employment Policy](#) (ODEP) and [Job Accommodation Network](#) (JAN) should contract with patient advocacy organizations to more widely disseminate their Long COVID webpages, which have many high-quality resources that workers may not be aware of.

¹ Approximately [10-30%](#) of [COVID-19 survivors](#) experience significant new, returning, or ongoing symptoms months after their acute infection. “Long COVID” - also known as [post-COVID conditions](#) - is a heterogeneous collection of multi-system symptoms that is often highly debilitating and can significantly impact people’s ability to perform daily activities, work, and attend school. A majority of people with Long COVID have symptoms consistent with already known post-infectious chronic illnesses, such as **Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)**, dysautonomias including **postural orthostatic tachycardia syndrome (POTS)**, and **Mast Cell Activation Syndrome (MCAS)**. Many people with Long COVID are being diagnosed with these conditions. We refer to this collection of illnesses as “**Long COVID and associated conditions.**” See also White House [fact sheet](#) on Long COVID and associated conditions, including ME/CFS, dysautonomia, and MCAS.



**PATIENT-LED
RESEARCH
COLLABORATIVE**

2. Update JAN's [Chronic Fatigue Syndrome](#) page to align with the CDC's [diagnostic criteria](#) for ME/CFS and guidance on managing its hallmark symptom, [post-exertional malaise](#) (PEM).²
3. ODEP can help with public education for workers and vocational rehabilitation centers about Long COVID, specifically including proper management of PEM, which will ensure that more workers can [stay in the workforce](#). See #MEAction's education campaign [#StopRestPace](#), and [guide on pacing](#) for symptom management.
4. **Employee Benefits Security Administration (EBSA)** benefits advisors should track all [complaints](#) received related to LCAC to identify trends in how these claims are being handled by disability insurance plan administrators.
5. **EBSA** should issue **regulations, opinions** or [information letters](#) on Section 503 of ERISA (29 USC Sec. 1133), that state:
 - It is not a **full and fair review** of a disability insurance claim if “**objective evidence**,” including positive COVID antigen or serology test results, are required as a condition of approving benefits where no such requirement appears in the plan.
 - It is not a **full and fair review** if a claim for LCAC is **analyzed solely as a mental health limitation** and is deemed to be limited to 24 months of benefits under a plan's mental illness limitation.
 - It is not a **full and fair review** if a claim that is based on **patient-reported symptoms** is denied solely due to the lack of **objective evidence** when their illness does not yet have a diagnostic test or other objective evidence associated with it.
 - Mental illness limitations of disability benefits (i.e. 24 months of benefits) are incompatible with [mental health parity](#) laws. Mental health and self-reported conditions must not receive inferior or limited health benefits to that of other conditions.
 - All **denial decision letters** must include an advisement: “**you have the right to seek counsel to assist with your appeal.**” Many claimants don't realize that any information submitted must be considered by the plan administrator, and without counsel they may collect insufficient information to support their case upon appeal.
6. The **Bureau of Labor Statistics** should request the Census Bureau to [add questions](#) to the Current Population Survey, and any other relevant survey instruments, to track Long COVID prevalence and its impacts on work.

² PEM is a worsening of symptoms after exertion (physical, cognitive, emotional, sensory, orthostatic) that can have a delayed onset and last for extended periods of time. It is often not well-understood or properly managed and has also been [reported](#) by many with Long COVID.