

Recommendations for Employers, Insurers, Human Resource Personnel and Rehabilitation Professionals on Return to Work for People Living with Long COVID

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What is Long COVID?

- According to the World Health Organization, Long COVID (also called Post COVID-19 Condition) "occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis"¹. Approximately 1 in 5 people have a **health condition** that might be related to their SARS-CoV-2 infection such as neurologic and mental health conditions, kidney failure, heart disease, lung disease and blood clots and vascular issues².

What causes Long COVID?

- Research is ongoing into the causes and risk factors for **Long COVID**. Studies are pointing to ongoing viral persistence, microscopic blood clots, autoimmune dysfunction and tissue damage³⁻⁵. Unfortunately, many routine diagnostic tests such as bloodwork, X-rays, and MRI's may be normal, and specialized testing (even tests for SARS-CoV-2) may be unavailable. This can make symptoms hard to explain or manage, and leaves people feeling misunderstood or abandoned by their healthcare providers².

Long COVID Symptoms

- Over 200 symptoms have been attributed to Long COVID⁶. The most common symptoms reported are disabling fatigue, shortness of breath, chest pain, cognitive dysfunction (brain fog or brain fatigue), dizziness and Post Exertional Symptom Exacerbation (PESE) or Post Exertional Malaise (PEM)⁶⁻⁸. **PESE/PEM** describes a worsening of a variety of symptoms such as fatigue or cognitive dysfunction after even minimal exertion. Thinking, socializing, and doing daily activities of living (like showering or cooking) can bring on PESE/PEM⁹.

Symptoms Are Episodic

- Symptoms can come and go and can be unpredictable in nature; people can look and perform fine one day, but the next day they are unable to get out of bed. Clusters of symptoms or health challenges can overlap and "fluctuate and change over time," referred to as **episodic disability**¹⁰. The 'invisible' features of episodic disability can make it difficult for those living with Long COVID to describe their health challenges to family, friends, employers, or health providers.

Episodic Disability and Implications for Employment

Someone living with Long COVID may experience **physical** and/or **cognitive** health challenges that result in difficulties carrying out regular daily activities of living, limiting energy available for work.

These **health challenges** may create barriers to social inclusion and it may be difficult for people with Long COVID to engage in pre-illness life roles or meaningful employment.

Returning to work might be possible for some, but it is often at the expense of participation in other life roles (ie: familial, household, leisure activities). This should be taken into account when considering employment.

Rehabilitation Management

The episodic and unpredictable nature of Long COVID means that **rehabilitation may look very different** from other types of injuries or illness. The exertion of attending appointments may be more harmful than helpful; cognitive challenges may create barriers to communication as well as information retention. Flexibility in delivery of care is key. Some examples provided by community experts with lived experience are:

- Using telerehabilitation instead of clinic appointments
- Reducing the number of appointments per week and recognizing that people may not be well enough to attend
- Providing written summaries of recommendations, treatments, resources, and plans
- Scheduling consistent dates and times for appointments

Rehabilitation in Long COVID should be disability focused, goal-oriented, and person-centred. It should focus on function and be tailored to an individual's goals, abilities, and interests¹⁰.

Safety Considerations: *PESE/PEM should be screened for using the DePaul Symptom Questionnaire¹¹.* If PESE/PEM is present, exercise is contraindicated. **Rehabilitation** for people with PEM/PESE should be focused on symptom stabilization using a **STOP/REST/PACE** protocol that has been developed by people with Myalgic Encephalomyelitis (ME), a chronic debilitating condition that is rooted in post infectious illness⁹. This approach may mean a dramatic reduction in activity level^{8,9} and expectations/goals should reflect a much slower process/longer recovery time.

Health professionals working with people with Long COVID are advised to increase their knowledge and understanding of the unique needs Long COVID presents⁸⁻¹⁰.

Assessing for Return to Work

For many with Long COVID (especially those with PESE/PEM and/or **dysautonomia**), traditional means of measuring fitness for return to work may be inappropriate and/or contraindicated. For example, Functional Capacity Evaluations (FCEs) often overestimate a worker's ability because they don't take into consideration the latent effects of activity¹². Someone living with Long COVID may be able to perform a task during an FCE, but then be bedbound for days after. Alternative measures may include functional interviews¹³. Recent research has also indicated that Patient Reported Outcomes can identify Long COVID with a high level of accuracy⁷ and are therefore a credible tool to use. Appropriate measures include those that consider the impact of Long COVID on quality of life and measures of disability. Recommended questionnaires include:


- **WHO Disability Assessment Schedule 12 (WHO-DAS)¹⁴**
- **Patient Reported Outcome Measurement Information System (PROMIS)¹⁵**
- **Fatigue Severity Scale¹⁶**
- **Good Day/Bad Day Questionnaire¹⁷**
- **Yorkshire Rehabilitation Scale¹⁸**

Return To Work Recommendations

Long COVID presents unique challenges for returning to the workplace. Due to its unpredictable and episodic nature, a return-to-work plan may not follow a straightforward trajectory. Be prepared for pauses or a longer course to return to full duties. Based on other chronic and episodic conditions, Return to Work plans should be individualized and tailored to each individual's needs and responses to activity¹⁹. Recommendations include²⁰⁻²⁴:

- **Recognizing the episodic and unpredictable nature of Long COVID**
- **Prolonged phased return**
- **Suitable workplace accommodations**
- **Remote work**
- **Flexible work hours**
- **Reduced physical and cognitive workload**
- **Altered tasks, longer time to complete tasks**
- **Rest-time accommodations**

**It is possible that some people will not recover. Some may be unable to return to their "pre-illness" employment, or any employment situation. There must be room for the possibility of any of these outcomes while supporting people with Long COVID.*

 **Recommendations on a Canadian approach to Long COVID and Episodic Disability can be found here.**

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Additional Resources

Long COVID Physio - www.longcovid.physio

Physios for M.E. - www.physiosforme.com

Work Well Foundation - www.workwellfoundation.org

Dysautonomia International - www.dysautonomiainternational.org

Postural Orthostatic Tachycardia Syndrome (POTS) UK - www.potsuk.org

World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy, 2021. ISBN: 978-1-914952-00-5.

<https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL-2021.pdf>

World Health Organization Clinical management of COVID-19. Living Guideline. September 2022

<https://app.magicapp.org/#/guideline/6471>

Canadian Physiotherapy Association – Long COVID Resource Page - <https://physiotherapy.ca/advocacy/advocacy-updates/recent-advocacy/national-physiotherapy-month-2022/long-covid-resource-page/>

NICE (National Institute for Health and Care Excellence) Cautions against graded exercise therapy for patients recovering from COVID-19: <https://www.bmj.com/content/370/bmj.m2912>

Realize Canada. The Pandemic Pandora's Box: Long COVID and Episodic Disability. <https://www.realizecanada.org/wp-content/uploads/The-Pandemic-Pandoras-Box.pdf>

Long COVID Resource Page: https://www.realizecanada.org/documents/?_sf_s=covid

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Authors: Jessica DeMars PT, Kelly K. O'Brien PT

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