realize

FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

DECEMBER 3, 2022

Recommendations for Employers, Insurers, Human Resource Personnel and Rehabilitation Professionals on

Return to Work for People Living with Long COVID

Table of Contents

How to Use

This is a living document that is continually updated based on emerging evidence in the field. The reference list provides scientific support to statements within the document and **hyperlinks** provide an enriched understanding of concepts that will reach the broader public.

How to Cite

DeMars J, O'Brien KK, Minor A, Graham K, Goulding S, Brown DA, Gross D; *Recommendations for employers, insurers, human resource professionals on return to work for people living with Long COVID.* December 1, 2022; Available at: **https://www.realizecanada.org/documents/recommendations-for-employers-insurers-human-resource-personnel-and-rehabilitation-professionals-on-return-to-work-for-people-living-with-long-covid/**

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 issues[2]. It is estimated that 1.4 million people are living with Long COVID in Canada and 2.2 million in the United Kingdom[3,4] and there are many millions of people living with Long COVID all over the world[5].

Watch this **video** on why it's called Long COVID.

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 damage[6-8]. 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 providers.[2]

Long COVID Symptoms

Over 200 symptoms have been attributed to Long COVID[2,4,5,9]. **Common symptoms** reported are disabling **fatigue**, shortness of breath*, chest pain*, **cognitive dysfunction** (brain fog or brain fatigue), **dizziness in sitting or standing** and Post Exertional Symptom Exacerbation (PESE) or Post Exertional Malaise (PEM).[9,10] **PESE/PEM** also referred to as post-exertional malaise (PEM), is defined as "the worsening of symptoms that can follow **minimal** cognitive, physical, emotional, or social activity, or activity that could previously be tolerated".[10] Thinking, socializing, and doing daily activities of living (like showering or cooking) can bring on PESE/PEM.

*Please refer to safety considerations on page 7

Symptoms are Episodic

Symptoms can **come and go**, include both physical and cognitive health challenges, and be unpredictable in nature. Clusters of symptoms or health challenges can overlap and "fluctuate and change over time," referred to as **episodic disability**.[11,12,13] 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.[13]

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.[14]

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 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 interests[10,11].

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 tele-rehabilitation 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 interests[10,11].

Safety Considerations

The World Health Organization provide **strong recommendations** that "exertional desaturation and cardiac impairment following COVID-19 should be ruled out and managed before consideration of physical exercise training. While orthostatic intolerance and post-exertional symptom exacerbation (PESE) are amenable to rehabilitation, their presence will require interventions to be modified in view of these diagnoses for rehabilitation to be safe[10]".

PESE/PEM should be screened for according to WHO clinical guidelines for rehabilitation[15].

If PESE/PEM is present, exercise is contraindicated. **Rehabilitation** for people with PEM/PESE should be focused on symptom stabilization[15] 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 illness. This approach may mean a dramatic reduction in activity level and expectations/goals should reflect a much slower process/longer recovery time.

Employers, insurers, and health professionals working with people with Long COVID are advised to **increase their knowledge** and understanding of the unique needs Long COVID presents[10-11].

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 activity[16]. 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 interviews[17]. Recent research has also indicated that Patient Reported Outcomes can identify Long COVID with a high level of accuracy[18] 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:

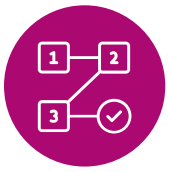
- **De Paul Symptom Questionnaire**
- **WHO Disability Assessment Schedule 12** (WHO-DAS)
- **Patient Reported Outcome Measurement Information System** (PROMIS)
- **Fatigue Severity Scale**
- **Good Day/Bad Day Questionnaire**
- **Yorkshire Rehabilitation Scale**

Recommendations for Return to Work

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 activity.[19]

Recommendations include[20-25]:

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.

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.
www.world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL-2021.pdf

Canadian Physiotherapy Association – Long COVID Resource Page
www.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:
www.bmj.com/content/370/bmj.m2912

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

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

Chartered Institute of Personnel and Development (CIPD) (2022) Working with long COVID: Research evidence to inform support. London: https://www.cipd.co.uk/Images/long-covid-report-feb-22_tcm18-106089.pdf

CIPD Website*:
https://www.cipd.co.uk/knowledge/fundamentals/relations/absence/long-covid-guides#gref

*also includes webpages for guides for professionals, line managers, colleagues and employees, recovering workers, and managers.

References

1. Soriano JB, Murthy S, Marshall JC, Relan P, Diaz JV. A clinical case definition of post-COVID-19 condition by a Delphi consensus. *Lancet Infect Disease*. 22:e102-07 https://doi.org/10.1016/S1473-3099(21)00703-9
2. Centers for Disease Control (CDC). Long COVID or Post-COVID Conditions. July 11, 2022. https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html
3. Statistics Canada. Long-term symptoms in Canadian adults who tested positive for COVID-19 or suspected an infection, January 2020 to August 2022. https://www150.statcan.gc.ca/n1/daily-quotidien/221017/dq221017b-eng.htm
4. Office for National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 December 2022 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1december2022
5. Wulf Hanson S, Abbafati C, Aerts JG, et al. A global systematic analysis of the occurrence, severity, and recovery pattern of long COVID in 2020 and 2021. Preprint. https://www.medrxiv.org/content/10.1101/2022.05.26.22275532v1.full.pdf
6. Mehandru, S., Merad, M. Pathological sequelae of long-haul COVID. Nat Immunol 23, 194–202 (2022). https://doi.org/10.1038/s41590-021-01104-y
7. Pretorius E, Vlok M, Venter C, et al. Persistent clotting protein pathology in Long COVID/Post-Acute Sequelae of COVID-19 (PASC) is accompanied by increased levels of antiplasmin. *Cardiovasc Diabetol*. 2021; 20 (172). https://doi.org/10.1186/s12933-021-01359-7
8. Merad M, Blish CA, Sallusto F, et al. The immunology and immunopathology of COVID-19. *Science*. 2022; 375 (6585); 1122-1127. https://doi.org/10.1126/science.abm8108
9. Davis HE, Assaf GS, McCorkell L, et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact, *EClinicalMedicine*, Volume 38, 2021. https://doi.org/10.1016/j.eclinm.2021.101019
10. World Health Organization. Clinical management of COVID-19: Living guideline, 15. September 15, 2022. Post-exertional symptom exacerbation. https://app.magicapp.org/#/guideline/j1WBYn/section/jOpQqB
11. Brown DA, O'Brien KK. Conceptualising Long COVID as an episodic health condition. *BMJ Global Health*. September 22, 2021. https://gh.bmj.com/content/6/9/e007004
12. O'Brien KK, Brown DA, Bergin C, Erlandson KM, Vera JH, Avery L, Chan Carusone S, Cheung AM, Goulding S, Harding R, McCorkell L, O'Hara M, Robinson L, Thomson C, Wei H, St. Clair-Sullivan N, Torres B, Bannan C, Roche N, Stokes R, Gayle P, Solomon P. Long COVID and episodic disability: advancing the conceptualisation, measurement and knowledge of episodic disability among people living with Long COVID - protocol for a mixed-methods study. *BMJ Open*. March 7, 2022;12:e060826. doi: 10.1136/bmjopen-2022-060826 Available at: https://bmjopen.bmj.com/content/12/3/e060826.full
13. O'Brien KK, Brown DA, McDuff K, St. Clair-Sullivan N, Solomon P, Chan Carusone S, McCorkell L, Wei H, Goulding S, O'Hara M, Thomson C, Roche N, Stokes R, Vera JH, Erlandson KM, Bergin C, Robinson L, Cheung AM, Torres B, Avery L, Bannan C, Harding R. Conceptualising the Episodic Nature of Disability among Adults Living with Long COVID: A Qualitative Study. November 14, 2022. medRxix preprint; https://www.medrxiv.org/content/10.1101/2022.11.12.22282116v1
14. Cysique LA, Jakabek D, Bracken SG, et al. Post-acute COVID-19 cognitive impairment and decline uniquely associate with kynurenine pathway activation: a longitudinal observational study. medRxiv. June 7, 2022. https://www.medrxiv.org/content/10.1101/2022.06.07.22276020v1
15. World Health Organization. Clinical management of COVID-19: Living guideline, 15. September 15, 2022. Post-exertional symptom exacerbation. https://app.magicapp.org/#/guideline/j1WBYn/section/jOpQqB
16. Podell R, Dimmock ME, Comerford BB. Documenting disability in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS). *Work*. 2020; 66(2):339-352. https://doi.org/10.3233/wor-203178
17. Gross DP, Asante AK, Miciak M, Battie MC, Carroll LJ, Sun A, et al. Are performance-based functional assessments superior to semistructured interviews for enhancing return-to-work out-comes? Arch Phys Med Rehabil. 014;95(5):807–815. https://pubmed.ncbi.nlm.nih.gov/24502839/
18. Klein J, Wood J, Jaycox J, et al. Distinguishing features of Long COVID identified through immune profiling. *medRxiv* 2022.08.09.22278592; https://doi.org/10.1101/2022.08.09.22278592
19. Vink M, Vink-Niese F. Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies. Diagnostics (Basel). 2019; Sep 20;9(4):124. https://doi.org/10.3390/diagnostics9040124
20. COVID-19 Return to Work Guide. 2021. https://www.som.org.uk/COVID-19_return_to_work_guide_for_managers.pdf
21. COVID-19 Return to Work Guide for recovering workers. https://www.som.org.uk/COVID-19_return_to_work_guide_for_recovering_workers.pdf
22. Long COVID and Return to Work – What Works? A Position Paper from the Society of Occupational Medicine. August 2022. https://www.som.org.uk/sites/som.org.uk/files/Long_COVID_and_Return_to_Work_What_Works.pdf
23. European Agency for Safety and Health at Work. Impact of Long COVID on workers and workplaces and the role of Occupational Safety and Health. May 2022. https://osha.europa.eu/en/publications/impact-long-covid-workers-and-workplaces-and-role-osh
24. European Agency for Safety and Health at Work. COVID-19 infection and Long COVID – Guide for Managers. 2021. https://osha.europa.eu/en/publications/covid-19-infection-and-long-covid-guide-managers
25. Faculty of Occupational Medicine of the Royal College of Physicians. Guidance for managers & employers on facilitating return to work of employees with post-COVID syndrome. https://www.fom.ac.uk/wp-content/uploads/FOM-Guidance-post-COVID_employers-managers.pdf

Acknowledgements

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

This guidance document is a collaboration between Realize, Long COVID Physio, Canadian Physiotherapy Association, and the Rehabilitation Science Research Network for COVID, Temerty Faculty of Medicine, University of Toronto.

We thank community experts Alyssa Minor, Karen Graham, Susie Goulding, and Darren Brown for their contributions and review of this document.

realize
FOSTERING POSITIVE CHANGE FOR PEOPLE LIVING WITH HIV AND OTHER EPISODIC DISABILITIES

LONG COVID PHYSIO

Rehabilitation Science Research Network for COVID

TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO