

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 .....	2
How to Cite.....	2
What is Long COVID? .....	3
What causes Long COVID?.....	4
Long COVID Symptoms .....	4
Symptoms are Episodic .....	5
Episodic Disability and Implications for Employment .....	5
Rehabilitation Management.....	7
Assessing for Return to Work.....	8
Recommendations for Return to Work .....	9
Additional Resources .....	10
References.....	11

## 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.

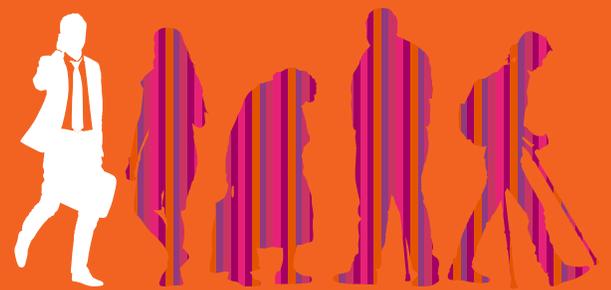
## How to Cite

DeMars J, O'Brien KK, Major 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/wp-content/uploads/Recommendations-for-RtW-doc-final.pdf>



## 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”<sup>1</sup>.



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

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<sup>6-8</sup>. 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.<sup>2</sup>

## Long COVID Symptoms

Over 200 symptoms have been attributed to Long COVID<sup>2,4,5,9</sup>. **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).<sup>9,10</sup> **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”.<sup>10</sup> 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**.<sup>11,12,13</sup> 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.<sup>13</sup>

## 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.<sup>14</sup>

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<sup>10,11</sup>.**



# 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<sup>10,11</sup>.**

## 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<sup>10</sup>”.

**PESE/PEM** should be screened for according to WHO clinical guidelines for rehabilitation<sup>15</sup>.

If PESE/PEM is present, exercise is contraindicated. **Rehabilitation** for people with PEM/PESE should be focused on symptom stabilization<sup>15</sup> 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.

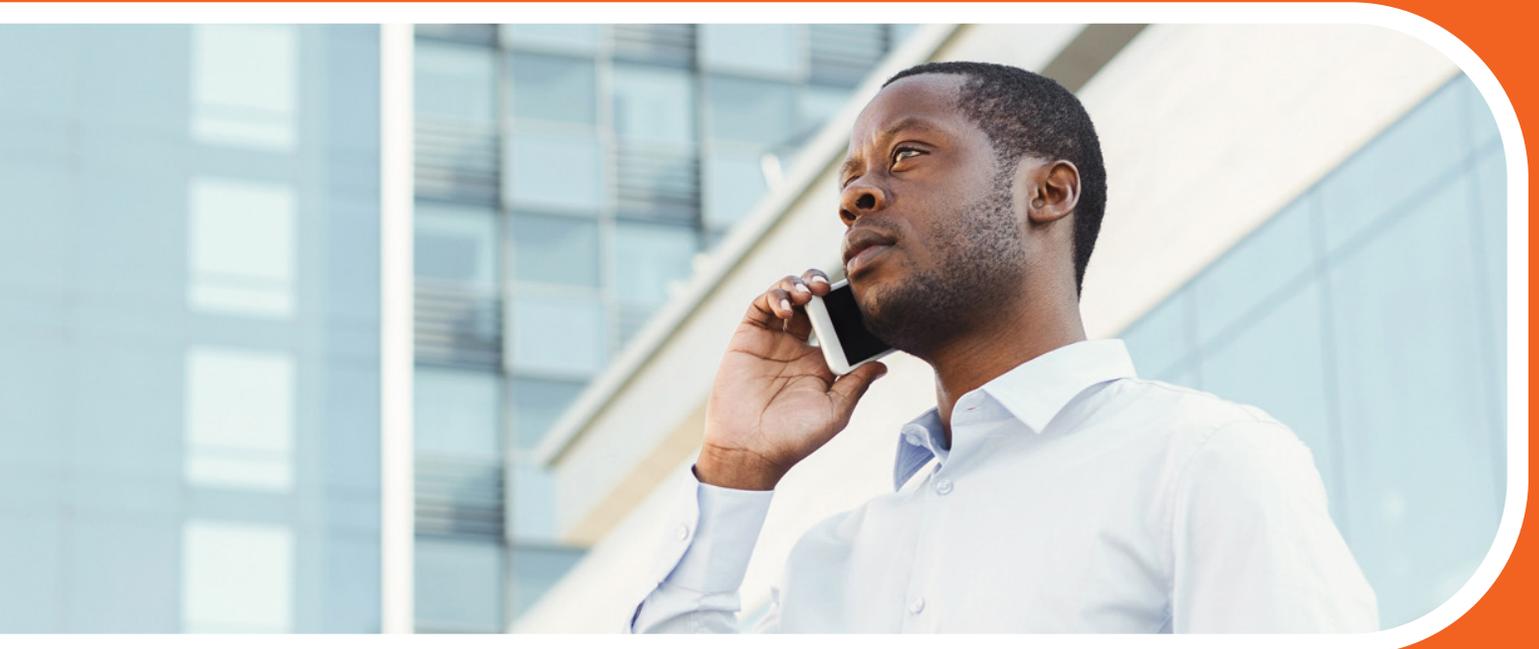
Employers, insurers, and health professionals working with people with Long COVID are advised to **increase their knowledge** and understanding of the unique needs Long COVID presents<sup>10-11</sup>.

# 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<sup>16</sup>. 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<sup>17</sup>. Recent research has also indicated that Patient Reported Outcomes can identify Long COVID with a high level of accuracy<sup>18</sup> 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**



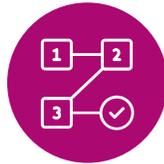
# Recommendations for Return to Work

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.<sup>19</sup>

## Recommendations include<sup>20-25</sup>:



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](http://www.longcovid.physio)

## **Physios for M.E.**

[www.physiosforme.com](http://www.physiosforme.com)

## **Work Well Foundation**

[www.workwellfoundation.org](http://www.workwellfoundation.org)

## **Dysautonomia International**

[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)

## **Postural Orthostatic Tachycardia Syndrome (POTS) UK**

[www.potsuk.org](http://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](http://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/](http://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](http://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](http://www.realizecanada.org/wp-content/uploads/The-Pandemic-Pandoras-Box.pdf)

## **Long COVID Resource Page**

[www.realizecanada.org/documents/?\\_sf\\_s=covid](http://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](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.

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# Acknowledgements

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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.