

## **APPENDIX – POST-COVID CONDITION INFORMATION AND RESOURCES (Updated June 2023)**

### Definition of Long Covid

PCC is well known and accepted by the World Health Organization (WHO) and by healthcare professionals across specialty areas. In addition, Ontario Health further recognizes PCC or Long COVID as a diagnosis and published “Post COVID-19 Condition: Guidance for Primary Care”<sup>1</sup> to support physicians managing this complex multisystem illness. Effective January 13, 2023 there is a fee code for reporting PCC assessment and management to Ontario Health Insurance (OHIP).

Patient accepted to the Unity Health Toronto Post-COVID program are individuals who meet the WHO criteria for diagnosis with PCC (Clinical Case Definition, WHO, October 6, 2021)<sup>2</sup>:

*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. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.*

### Long Covid Is an Episodic Disability

PCC results in symptoms that are episodic, unpredictable, and complex. A study of individuals living with PCC in Canada, Ireland, UK, and USA describes fluctuations in their health conditions (“crashes”, “flare-ups”) and consequently, in their ability to participate in their usual activities. The authors state that PCC is to be approached as a potential chronic illness.<sup>3</sup> The trajectory of the individuals in the study reflects “an absence of a progressive path from illness to wellness recovering from COVID-19”.<sup>3</sup> Their condition affects participation in all domains, including family, social, community, and employment. A recent review of PCC mechanisms, symptoms and potential management is available online.<sup>4</sup>

### Fatigue and Post-Exertional Malaise or Post-Exertional Symptoms Exacerbation (PEM/PESE)

The nature and course of PCC places it within the framework of other post-acute infection syndromes.<sup>5</sup> Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), for example, is now thought to be a post-viral syndrome. Like those with ME/CFS, a large number of PCC patients exhibit a pattern of PEM, where mental or physical exertion can lead to extreme fatigue and exacerbation of symptoms, or the onset of new symptoms. This can even be the case in individuals whose work has no physically demanding component. The majority of individuals with PCC meet the criteria for an ME/CFS diagnosis based on standardized measures of PEM.

As defined by the Centers for Disease Control and Prevention (CDC)<sup>6</sup>:

*Post-exertional malaise (PEM) is the worsening of symptoms after even minor physical, mental or emotional exertion. For some patients, sensory overload (light and sound) can induce PEM. The symptoms typically get worse 12 to 48 hours after the activity or exposure and can last for days or even weeks.*

The pattern of PEM or post-exertional symptom exacerbation (PESE) is central to the episodic and unpredictable nature of PCC. PEM is only one of upwards of 200 reported symptoms that have been identified in individuals living with PCC.<sup>4</sup> Symptoms with the highest incidence include generalized fatigue, cognitive dysfunction, autonomic nervous system dysfunction, respiratory dysfunction, weakness, joint pain, and digestive disorders. Many of these symptoms overlap with those of other post-viral conditions.<sup>7</sup>

### Treatment of Long Covid

There are currently very few effective treatments for the varied and persistent symptoms of PCC<sup>4</sup>, and current best practice draws from management approaches used in similar and related conditions (ME/CFS).<sup>8</sup> Accordingly, our program aims to provide patients with an understanding of PCC and with tools that support self-management of their condition. **Due to PEM/PESE, traditional rehabilitation incorporating progressive graded exercise is contraindicated in illnesses like PCC.**<sup>9,10</sup> The recommended approach is symptom-titrated and progression is determined based on the patient's individual tolerance to physical/cognitive activities.<sup>9</sup> A return to previous schedules, workload and activities that are not matched to the patient's level of recovery is likely to result in relapse.

### Prognosis of Individuals with Long COVID

Although longitudinal research remains in the early stages, it appears that in some cases, some aspects of PCC are likely to persist over the long term, resulting in a chronic disability. Some of the factors that might affect prognosis include<sup>4,12</sup>.

- the length of time since symptom onset without substantial recovery
- development of worsening and new symptoms since onset
- the absence of targeted treatment for PCC at this time

### Return to Work and School

Based on the clinic's experience working with patients with PCC, recognizing the episodic nature of Long COVID is required during any return-to-work discussion. Any plan to return to work or school should consider a prolonged gradual return and be tailored to an individual's needs and responses to activity. The following recommendations reaffirm the symptom-titrated approach in PCC and that any progression should be determined based on the client's individual tolerance to activity.

1. Suitable workplace accommodations
2. Remote work
3. Flexible work hours
4. Reduced physical and cognitive workload (or course load)
5. Altered tasks, longer time to complete tasks (including exams, assignments)
6. Rest-time accommodations<sup>11</sup>

Ongoing support and information for Family Physicians

Updated information and resources on how to support and manage your patient's care can be found on the Ontario College of Family Physicians website under "Post-COVID Condition (Long COVID)".<sup>1</sup>

## References

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