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EDITORIAL

What is Safe Long COVID Rehabilitation?

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Long COVID is a term coined and preferred by people with the condition that describes persistent effects of Coronavirus Disease (COVID-19) [1]. Long COVID is known by other names including "*Post COVID-19 Condition*" (World Health Organization (WHO)[2] and "*Post-Acute Sequelae of COVID-19*" (United States). Long COVID is estimated to affect more than 145 million people around the globe[3] and results in wide diversity of symptoms,[4] episodic disability,[5] reduced quality of life,[6] and work loss,[7] irrespective of hospitalisation or acute disease severity [8]. Improved understanding of appropriate health care and rehabilitation interventions to reduce the burden of Long COVID have been identified as an international research priority.[9].

In September 2022, the patient-led association Long COVID Physio organized the two-day online Long COVID Physio International Forum, bringing lived experiences to Long COVID, disability, rehabilitation, and research. Long COVID Physio is an international, patient-led association of physiotherapists (physical therapists) living with Long COVID and allies, working internationally across peer support, education, research, and advocacy [10]. At the Forum, a discussion session was held to address the question, "*What is Safe Long COVID Rehabilitation*?" This topic was of critical importance given that some have experienced complications such as acute events, symptom exacerbation, or deterioration following traditional approaches to rehabilitation (i.e., involving progressive loading, physical or cognitive activity, or exercise), as well as perceived lack of support from health care providers who at times question the validity of symptom reports.

The discussion session involved people living with Long COVID, clinicians, and researchers with expertise and experiences related to Long COVID rehabilitation. The 10 speakers involved in this session met in advance of the Forum to share experiences and ideas, identify potential themes for discussion, and deliberate proposed recommendations. These were then presented to the international community at the Forum where themes and recommendations were discussed, debated, solidified, and are presented in this editorial (summary available in Table 1).

1) *Safe Long COVID rehabilitation should include identifying red flags or complications where commencing rehabilitation could cause an acute event or deterioration.*

People living with Long COVID often experience worsening symptoms following activity, including physical tasks

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Table 1 Themes and Recommendations from the Long COVID Physio International Forum Discussion Session on Safe Rehabilitation of People Living with Long COVID

Theme	Justification	Recommendation
Avoiding Acute Events and Symptom Flare Ups	People living with Long COVID have experienced acute events, symptom exacerbation (i.e., Post-Exertional Symptom Exacerbation (PESE), or deterioration following traditional approaches to rehabilitation or other physical activity.	Rehabilitation professionals should screen for contraindications or precautions to activity and exercise prior to rehabilitation, plus incorporate modifications to rehabilitation interventions in the presence of PESE and orthostatic intolerances. The focus of rehabilitation is often stabilising fluctuations before building tolerance and activity.
Personalization	People living with Long COVID experience a wide diversity of symptoms, participation restrictions, and episodic disability.	Rehabilitation professionals should be flexible and tailor rehabilitation to the unique needs of each person living with Long COVID.
Facilitating Expectations	Recovery looks different for each person living with Long COVID and is often focused on mitigating disability, optimising functioning, and strategies to support living with disability, rather than a cure.	Rehabilitation professionals should hold clear and accurate expectations for rehabilitation from the beginning and help to inform clients, family members, employers, and other healthcare providers, or any others holding unrealistic expectations, about the role and scope of Long COVID rehabilitation.
Psychologically Supportive	People living with Long COVID need to feel heard and understood by their healthcare providers. Many experience disbelief and stigma, including from health professionals.	Rehabilitation professionals should be authentically non-judgemental and create psychologically safe spaces for rehabilitation.

or exertion. (i.e., Post-Exertional Symptom Exacerbation (PESE), also known as Post-Exertional Malaise (PEM)) [11]. Clinicians, including rehabilitation professionals, should screen for contraindications or precautions to activity and exercise interventions prior to rehabilitation, then refer to appropriate specialists for additional testing or intervention if needed. This includes screening for PESE as well as autonomic dysfunction. The WHO guideline provides a strong recommendation stating: *In adults with post COVID-19 condition exertional desaturation and cardiac impairment following COVID-19 should be ruled out and managed before consideration of physical exercise training. While orthostatic intolerance and PESE are amenable to rehabilitation, their presence will require interventions to be modified in view of these diagnoses for rehabilitation to be safe* [2].

Rehabilitation professionals should screen for physical, cognitive, social, and emotional triggers. Potential screening tools suggested for use are shown in Table 2. Beyond standardized tools, clinicians should conduct a thorough assessment through history taking and reporting of symptom experiences and patterns [12]. Detailed assessment involving a comprehensive patient-focused interview is necessary as some people living with Long COVID may not always think a symptom is relevant to the rehabilitation professional (e.g., heat intolerance, dizziness). Lastly, persons who previously had COVID-19 should be screened despite their reason for accessing rehabilitation, as they may have undetected Long COVID symptoms that may influence their overall health and safety with rehabilitation.

2) *Safe Long COVID rehabilitation should be personalized.*

People living with Long COVID experience a wide diversity of symptoms, participation restrictions, and episodic disability. Many experience dysregulation characterized by fluctuating symptoms typical of other post-viral syndromes, such as myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) [11, 12]. Rehabilitation should initially focus on symptom stabilization and strategies to sustain function without symptom exacerbation. This applies to cognitive activities and social interactions in addition to physical activities. Related to physical activity, rehabilitation professionals should re-consider the standard use of strenuous physical performance testing (i.e., functional capacity evaluation), especially in people with PESE. People living with Long COVID may be able to perform the test, but later experience profound worsening of symptoms and deterioration in functioning. If performance testing or other forms of physical activity are deemed appropriate, rehabilitation professionals should follow-up in subsequent days to determine whether symptom exacerbation was experienced [13].

3) *Safe Long COVID rehabilitation should be founded within accurate expectations.*

Return to health after COVID-19 looks different for each person and often does not progress linearly or with certainty. Improvement may be slow and since the prognosis for full recovery is uncertain, rehabilitation often aims for mitigating disability, optimising function, and establishing strategies to support living with disability, rather than a cure. This may require rehabilitation professionals to reframe their own assumptions and expectations as healthcare providers [14]. Rehabilitation professionals should support people living with Long COVID with anticipating and managing

Table 2 Available Screening Tools for Detecting Potential Complications from Rehabilitation in People Living with Long COVID

Name of Assessment or Screening Tool	Brief Description of Screening Tool	Resources
DePaul Symptom Questionnaire – Post-Exertional Malaise (DSQ-PEM)	This is a brief, standardized questionnaire that aims to detect experiences with post-exertional malaise [16].	May be downloaded and used free of charge from: https://csh.depaul.edu/about/centers-and-institutes/ccr/myalgic-encephalomyelitis-cfs/Pages/measures.aspx
10-Minute NASA Lean Test	Positional test that assesses for postural orthostatic tachycardiasyndrome.	Instructions are available from: https://solvecfs.org/wp-content/uploads/2021/07/10-Minute-NASA-Lean-Test-Clinicians.pdf
Pulse Oximetry	Pulse oximetry under clinical supervision has been recommended to screen for exertional desaturation using tests such as the 1-minute sit-to-stand test [2], the 40-step walk test [15], or during home observation. A drop in pulse oxygen saturation of more than 3–4% from baseline or to 94% or below is considered desaturation [2]. Exercise testing for exertional desaturation should be avoided or modified (within tolerable limits for the individual) in the presence of Post-Exertional Symptom Exacerbation.	Pulse oximeter is required. Rapid exercise tests for exertional desaturation are not recommended for use outside a supervised care setting if resting pulse oximeter saturation is < 96% [15].
Adapted Autonomic Profile (aAP)	The adapted Autonomic Profile (aAP) is a home-based test for the evaluation of neuro-cardiovascular autonomic dysfunction. This screening test may clarify the relationship between symptoms and common triggers in daily life, informing self-management and rehabilitation of episodic conditions such as Postural Orthostatic Tachycardia Syndrome.	The test involves measuring blood pressure and heart rate at various times throughout the day while at home. Detailed instructions for conducting the aAP have been published [17].

setbacks. Traditional goal setting may not be helpful, as missing goals can often lead to frustration.

4) *Long COVID rehabilitation should be psychologically safe and supportive.*

People living with Long COVID and other energy limiting, post-infectious, chronic complex conditions, need to feel heard and understood by their healthcare providers. Many people living with Long COVID face disbelief and stigma, including from health professionals [1]. Rehabilitation professionals should be authentically non-judgmental, respect that people living with Long COVID are experts in their own health and condition, and create a supportive environment that is psychologically safe and inclusive. It is important to celebrate small successes and crucial that people living with Long COVID are not blamed for exacerbations or setbacks (i.e., "you didn't pace well enough").

Since the Forum, the WHO published guidelines for clinical management of COVID-19 that include guidance on rehabilitation of adults living with Long COVID,[2] further supporting these recommendations. Rehabilitation professionals are encouraged to increase their capacity and knowledge of Long COVID, specifically referring to evidence-informed guidelines [2, 15] to gain confidence and competence in the assessment, treatment and management of Long COVID. This includes learning about safe and effective rehabilitation of post-infectious complex chronic conditions, energy limiting conditions, and episodic disability.

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