Primary Care Toolkit: Supporting Patients with Long COVID

A practical, evidence-informed guide for identifying, assessing and managing patients with Long COVID in community settings.

This toolkit was developed by the Post-Covid Recovery Clinic (PCRC) interdisciplinary team with input from primary care throughout BC. It is intended to support primary care providers as the first line in assessment and management of patients with post-COVID symptoms. For patients who may benefit from more specialized care, referrals to the PCRC can be made using this form: Post-COVID Recovery Clinic (PCRC) Referral Form

IDENTIFY

Long COVID Definition

Long COVID has had several definitions. The National Academies of Sciences, Engineering, and Medicine (NASEM) defines long COVID as "an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems."

Clinically, long COVID can be best understood as an umbrella term for persistent symptoms and syndromes that are new or worsened after a SARS-CoV-2 infection.

When to Suspect

The following are common symptoms of long COVID:

- Fatigue, "brain fog," shortness of breath, chest pain, dizziness, or palpitations
- Post-exertional malaise (PEM)- symptom worsening after physical or mental exertion
- Orthostatic intolerance- suggestive of postural orthostatic tachycardia syndrome (POTS)
- Persistent functional impairment in daily or work activities

Initial Questions to Guide Identification:

1. Are symptoms persistent?
2. Do symptoms worsen after exertion (PEM)?
3. Do they improve when lying down or worsen with standing (POTS)?
4. Is the patient struggling to function at home or work?

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ASSESS

A. Rule Out Alternative Diagnoses

Focus testing on excluding common and treatable causes of persistent symptoms. For detailed pre-referral testing guidance, see PC-ICCN Workup Checklist (Oct 2023).

Symptom	Tests (as indicated)	Common Differentials to Exclude
Fatigue/" brain fog"	CBC, ferritin, iron studies, electrolytes, creatinine, liver function tests, TSH, vitamin B12 level, HbA1c, PHQ-9 (depression), GAD-7 (anxiety), sleep study	Anemia, thyroid dysfunction, vitamin deficiency, depression, sleep apnea, deconditioning, diabetes
Shortness of breath	Chest x-ray, ECG, BNP, full pulmonary function tests, CT chest, echocardiogram	Asthma/COPD, cardiac dysfunction, deconditioning, dysfunctional breathing, pulmonary fibrosis
Chest pain and/or palpitations	ECG, troponin, Holter monitor, chest x-ray, cardiac stress test, echocardiogram	Arrythmia, angina, inappropriate sinus tachycardia, myocarditis/pericarditis, anxiety/panic episodes, hyperthyroidism, stimulants
Dizziness	CBC, ferritin, iron studies, ECG +/- Holter monitor, orthostatic vital signs, Dix-Hallpike maneuver, AM cortisol	Anemia, iron deficiency, orthostatic hypotension, arrhythmia, BPPV, persistent postural perceptual dizziness, adrenal insufficiency

If no clear alternative and history of confirmed or suspected SARS-CoV-2 infection ⇒diagnose long COVID (suspected)

B. Screen for Key Syndromes

1. Post-Exertional Malaise (PEM)

Definition:	Worsening of symptoms following even minor physical, cognitive or social/emotional exertion or stress.
Screen:	DePaul Symptom Questionnaire and scoring criteria
Typical profile:	Exertion leads to worsening of any Long COVID symptoms including fatigue, pain, breathlessness or brain fog lasting >24h. Symptom exacerbation is often delayed 24 to 72 hours.

2. Postural Orthostatic Tachycardia Syndrome (POTS)

Diagnostic criteria:	HR ⇑ >30 bpm (> 40 bpm <20 y) within 10 min of standing, without significant orthostatic hypotension (BP drop ≥ 20/10 mm Hg), very frequent symptoms of orthostatic intolerance, symptom duration ≥3 months
Screen:	1. Dizziness/light-headedness when standing? 2. Relief when lying down?
Confirm:	10-Minute Stand Test Instructions

C. Assess Functional Impact

Document:	• Consider ME/CFS diagnostic criteria if PEM predominate.
	• Traditional functional capacity evaluations are not appropriate in this population as they do not consider PEM and have the potential of worsening health. The following can be used instead:
	  ○ FUNCAP
	  ○ Good Day, Bad Day Assessment

Resource:	Risk of PEM from FCE Statement Letter

MANAGE

A. Manage PEM (Energy Limitation)

Principle	Practical Guidance
Educate	Overexertion worsens recovery; encourage aggressive rest and pacing and engagement in PCRC virtual group education program. Messaging: Self- management is hard, you deserve support, supported self-management is available at PCRC. Please sign up for groups.
Pacing	Encourage "energy envelope" approach to decrease the frequency and intensity of PEM. Functional capacity decreases with repeated bouts of PEM and can improve with living below the threshold for symptoms.
Rehabilitation	Avoid graded exercise therapy (contraindicated). Use symptom-titrated activity. Attend physiotherapy and occupational therapy groups at the PCRC. **Rehabilitation for PEM is different than traditional deconditioning rehabilitation**
Contributors	Optimize sleep, hydration, nutrition, mental and emotional well-being.
Medications	No prescription medications are approved for the treatment of PEM in long COVID and/or myalgic encephalomyelitis/ chronic fatigue syndrome, and none are specifically recommended by WHO or CAN-PCC Guidelines. Off-label medications that have been used include low-dose naltrexone (0.5 to 4.5mg daily), low-dose aripiprazole (0.25 to 4mg daily), and modafinil (100 to 400mg daily).

Resources: CAN-PCC Guidelines; WHO Clinical Management of Post-COVID-19 Condition (Aug 2023)

- Pacing and energy management recommended; graded exercise not advised (p.115)
- Return to work guidance; phased, flexible return to activity (pp.125-126)

B. Manage POTS (Orthostatic Intolerance)

Approach	Examples
Non-pharmacologic (first line)	Increase fluids (2-3L/day), increase salt (8-10 g/day or 2 tsp table salt), compression garments (ideally waist or thigh-high), avoid prolonged standing/heat (encourage shower chair), gradual position change, recumbent exercise (needs to be done cautiously if they are PEM positive, please refer to PCRC for physiotherapy guidance).
Pharmacologic (specialist-guided)	If tachycardia and palpitations predominant: beta blockers like propranolol 10-20 mg po QID (first line), or ivabradine 5 mg po BID If supine hypotension: midodrine 2.5-10 mg po TID (first line), or pyridostigmine 30-60 mg po TID Additional options: fludrocortisone, methyldopa, clonidine
Monitor	HR/BP, hydration, activity and symptom diary.

Resources: 10-Minute Stand Test Instructions; Canadian Journal of Cardiology Consensus Statement; CMAJ Review; CAN-PCC Guidelines

C. Support Function and Return to Work

General Function:	• Sparc Pass
	• Medical Equipment Provision Program
	  ○ People often benefit from equipment for energy conservation and POTs management.
	  ○ Ex. shower chair, perching stool, four- wheeled walker with seat
	• Handy Dart
	• Referral to Home Health for support with ADLs, mobility, fall prevention.

Work:	• Many individuals with PEM require time away from work to stabilize symptoms before attempting a return. • Medical documentation is often required to outline functional limitations and justify time off work, an individualized, prolonged and flexible return-to-work plan and specific workplace accommodations. • Before returning to work, individuals should be able to consistently manage basic daily living activities and some leisure with symptom stability and tolerate the upright time required for a full work shift without triggering PEM. Not all individuals with PEM will be able to return to work. • Accommodations should support autonomy and enable self-management strategies. • Given the fluctuating nature of PEM, functional limitations should be based on the individual's worst day.
Resources:	Realize Canada: Long COVID and Work JDAPT/ACED Accommodation Guidance Common Long COVID Work Accommodations Guidance Resource Recommendations for Employers, Insurers, Human Resource Personnel and Rehabilitation Professionals on Return to Work for People Living with Long-COVID

D. Communicate and Support Patients

Goals:	• Validate experience, set realistic expectations, guide self-management, encourage gradual recovery and prevent misinformation.
Tips:	• Listen and validate: "Your symptoms are consistent with post-viral illness." • Normalize uncertainty around prognosis for Long COVID while offering that structured management has helped support improvements. • Encourage pacing as first step in structured management. • Support mental health by recognizing mental health can be impacted by the adjustment to post-viral illness. • Use scheduled follow-ups; avoid unnecessary testing. • Refer to reputable sources (PC-ICCN, BCCDC, WHO, McMaster) to avoid misinformation.
Resource:	CAN-PCC Guideline: Screening for Depression

References & Resources

- WHO Post-COVID Clinical Management Guideline
- Canadian Guidelines for Post COVID-19 Condition
- BCCDC Post-COVID Resources
- PHSA Post-COVID-19 Interdisciplinary Clinical Care Network Clinical Resources
- Primary Care Provider FAQs: Common Questions About Long COVID

For questions about PEM or post-COVID care, contact the RACE line (General Internal Medicine – Long COVID):

604-696-2131 or 1-877-696-2131 (Mon-Fri, 8am-5pm PST)