



ASSESSING DISABILITY IN LONG COVID

A rehabilitation perspective.

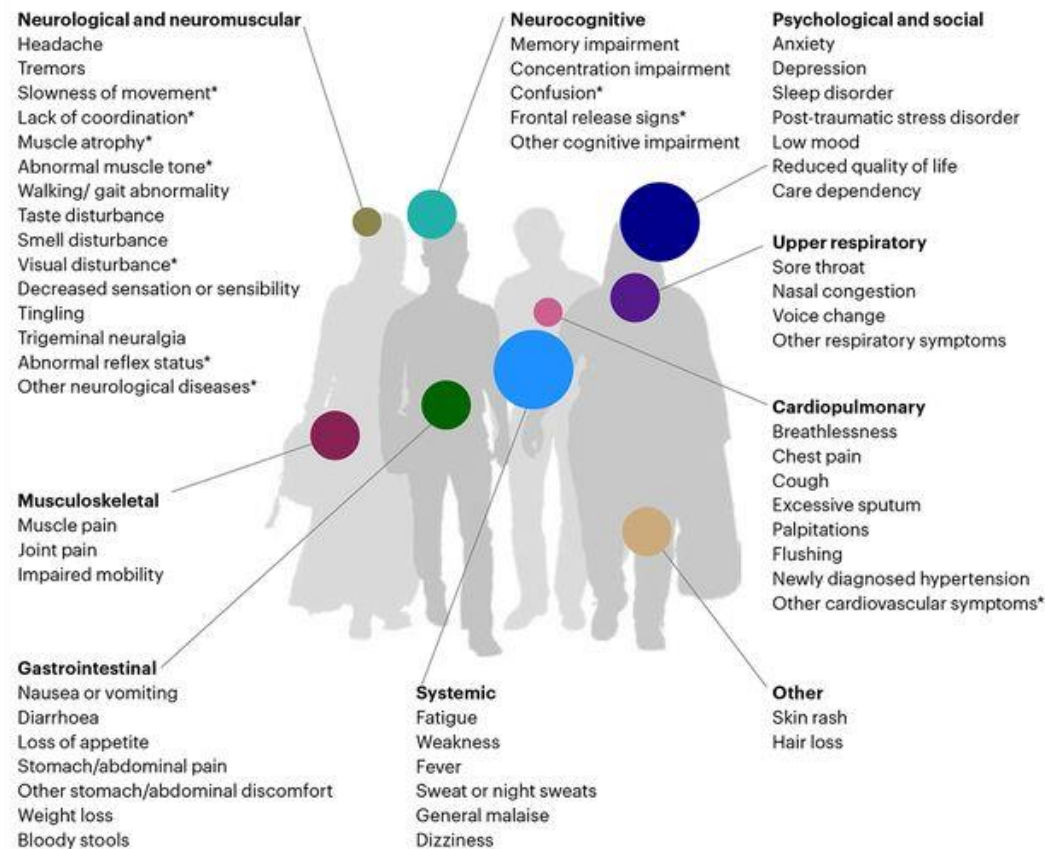
Jessica DeMars, PT

Long Covid symptoms and signs

Frequency:  Very common  Common  Less common

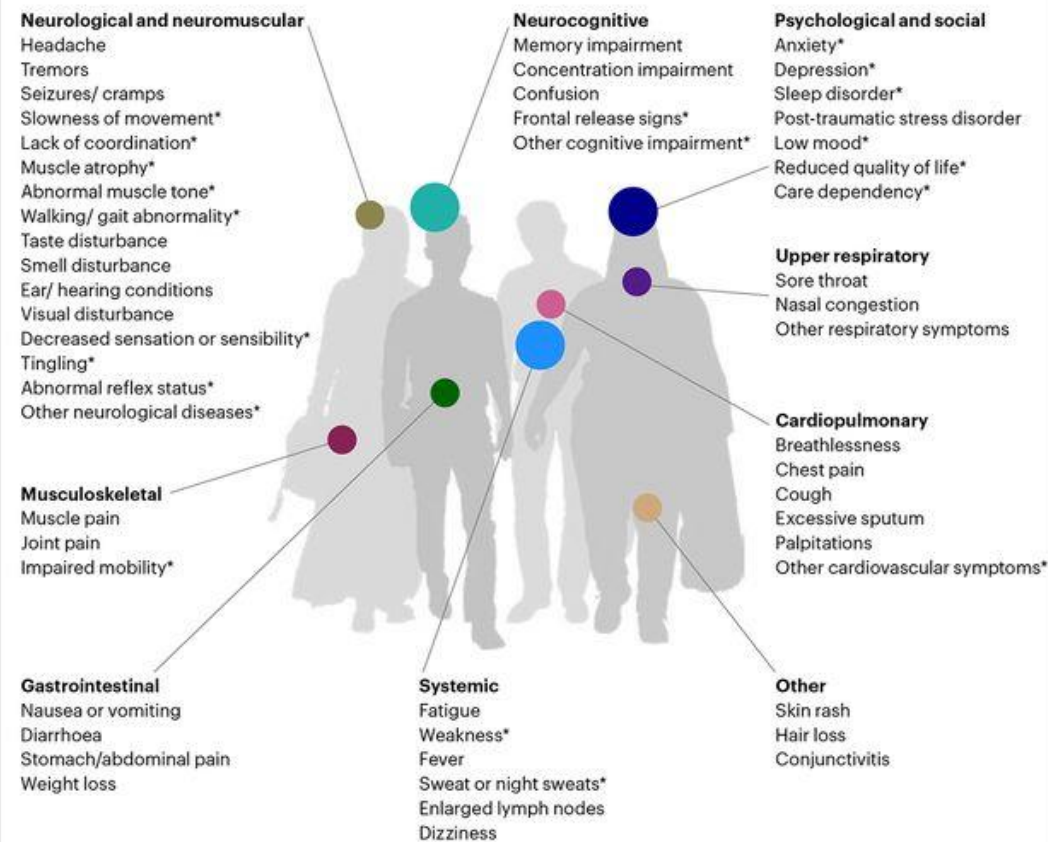
People hospitalised during acute phase of Covid-19

Based on 26 studies with 7147 people*



People non-hospitalised during acute phase of Covid-19

Based on 4 studies with 1168 people*



* Identified only in studies including both hospitalised and non-hospitalised people (9 studies including 2636 people)

Last updated 17 Mar 2021

Michelen M, Manoharan L, Elkheir N, et al. Characterising long COVID: a living systematic review. BMJ Global Health 2021;6:e005427. doi:10.1136/bmjgh-2021-005427

IMPACT ON FUNCTION

What effect does Long Covid have on daily life?

- 32% (28%) unable to live alone without assistance at 6 weeks
- 66% (72%) taken time off sick (median 60 days)
- 37% (33%) loss of income due to illness
- Being ill affected respondents' ability:
 - self-care 50% (42%)
 - domestic chores 84% (80%)
 - work 75% (78%)
 - childcare 36% (33%), caring for other adults 26% (25%)
 - mental health 64% (65%)

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Having LC meant serious effects on daily life. Common triggers of symptoms included physical activity (77%) stress (55%), sleep disturbance (47%) & cognitive activity (42%), but not all participants said they can always identify a trigger for worsening of symptoms.

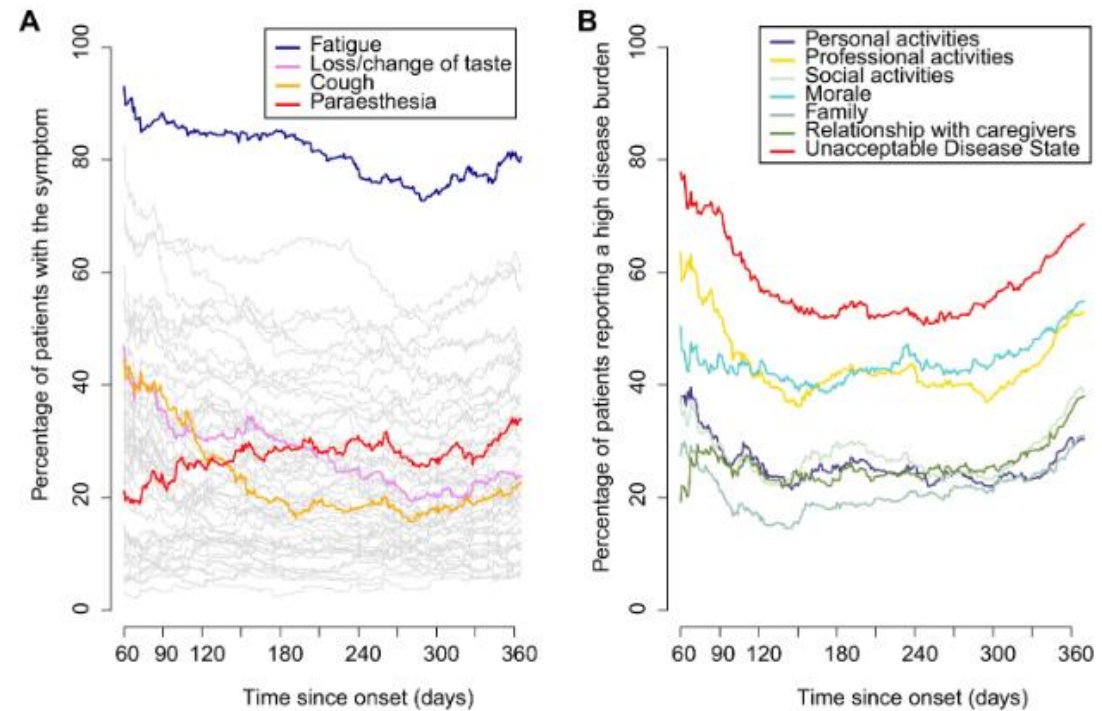
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IMPACT ON FUNCTION

Fig. 3: Day-by-day trends in the prevalence of post COVID-19 disease symptoms (A) and of their impact on patients' lives (B).

From: [Course of post COVID-19 disease symptoms over time in the ComPaRe long COVID prospective e-cohort](#)



ASSESSMENT STRATEGIES

Assessing the unassessable?

PHYSICAL ASSESSMENTS

- PEM/PESE must be screened for
- As per WHO Clinical Guidelines:
 - Post-exertional symptom exacerbation (PESE), 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 [340]
 - Post-exertional symptom exacerbation may not be mentioned spontaneously by individuals, due to unfamiliarity with the concept [346]. Clinicians should carefully assess for PESE in post COVID-19 condition, including PESE symptoms, triggers, duration, and change over time [350], while ruling out activity intolerance or reduced exercise tolerance which may be caused by respiratory, cardiovascular, and musculoskeletal conditions [293][322][353].

World Health Organization. Clinical management of COVID-19: Living guideline, 15. September 15, 2022. Post-exertional symptom exacerbation. <https://app.magicapp.org/#!/guideline/jlVBYn/section/jOpQqB>

DePaul Symptom Questionnaire Post-Exertional Malaise (DSQ-PEM)

For each symptom below, please circle one number for frequency and one circle for severity. Please complete the chart from left to right.
***Note:** If you have been experiencing long COVID for less than 6 months, only consider the weeks or months since your long COVID symptoms began.

	Frequency: Throughout the <u>past 6 months</u> , how <u>often</u> have you had this symptom?					Frequency: Throughout the <u>past 6 months</u> , how <u>much</u> has this symptom bothered you?				
	0 = None of the time 1 = A little of the time 2 = About half of the time 3 = Most of the time 4 = All of the time					0 = Symptom not present 1 = Mild 2 = Moderate 3 = Severe 4 = Very Severe				
1. Dead, heavy feeling after starting to exercise	0	1	2	3	4	0	1	2	3	4
2. Next day soreness or fatigue after non-strenuous, everyday activities	0	1	2	3	4	0	1	2	3	4
3. Mentally tired after the slightest effort	0	1	2	3	4	0	1	2	3	4
4. Minimum exercise makes you physically tired	0	1	2	3	4	0	1	2	3	4
5. Physically drained or sick after mild activity	0	1	2	3	4	0	1	2	3	4

For each question below, choose the answer which best describes your symptoms.

6. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?	Yes	No				
7. Do you experience a worsening of your fatigue/energy related illness after <u>engaging in minimal physical effort</u> ?	Yes	No				
8. Do you experience a worsening of your fatigue/energy related illness after <u>engaging in mental effort</u> ?	Yes	No				
9. If you feel worse after activities, how long does this last?	≤ 1 h	2-3 h	4-10 h	11-13 h	14-23 h	≥ 24 h
10. If you do not exercise, is it because exercise makes your symptoms worse?	Yes	No				

PHYSICAL ASSESSMENTS

- PEM/PESE must be screened for
 - Physical testing contraindicated for people with PEM/PESE
- Rule out additional red flags
 - Dysautonomia
 - Cardiac Impairment
 - Exertional Oxygen Desaturation

Resource: World Physiotherapy response to COVID-19 Briefing Paper 9: *Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise.*

DYSAUTONOMIA

- Symptoms include: fatigue, cognitive dysfunction, shortness of breath, racing heart, temperature intolerance, digestive dysfunction, sleep disturbance
- Orthostatic Intolerance Questionnaire (Bateman Horne Centre)
- 10 Minute NASA Lean Test
- COMPASS 31 (Composite Autonomic Symptom Score)

FUNCTIONAL LIMITATIONS

- Patient documentation: daily journal of symptoms and functional limitations
 - Include “good day” and “bad day” examples
- Documentation of medical signs
 - Orthostatic intolerance – measure HR/BP lying and standing
 - Palpable swollen lymph nodes, muscle tenderness
- Documentation of Symptoms
- Functional Evaluation*

From: R. Podell et al. Documenting disability in ME/CFS. *Work* 66 (2020) 339-352

Table 1
Severity of Symptoms Following 60-minute Typing Test²

Severity at Specified Time for a Patient with Widespread Pain ³ (Severity scale 0–10 with 10 the most severe)						
Symptom	Before test	At end of of test	1 hr. post-test	8-12 hrs. post-test	24 hrs. post-test	48 hrs. post-test
Fatigue	4	6	6	8	8	6
Cognitive Difficulties (“brain fog”)	5	5	5	7	7	5
Pain in Forearms	3	5	6	8	9	5
Pain in Wrist	2	4	6	8	9	5
Pain in Hands/Fingers	2	3	5	8	9	6
Pain in Upper Arms	2	4	6	7	8	6
Pain in Shoulders	2	3	4	5	6	4
Pain in Chest	3	4	4	4	6	3
Pain in Neck	0	1	2	3	4	4
Pain in Face	2	2	2	3	5	3
Pain in Head	0	0	1	1	2	1
Pain in Low Back	3	4	5	6	6	3
Pain in Upper Back	3	4	5	5	5	3
Pain in Legs	5	5	5	6	6	5

²Test on ME/CFS claimant with fibromyalgia comorbidity. ³The specific symptoms evaluated should reflect those that most impact the patient.

Table 2
Concerns with the Functional Capacity Evaluation in ME/CFS

The Functional Capacity Evaluation (FCE), as most often practiced, has at least four major problems when applied to ME/CFS [34]. By overestimating the claimant's capacity to work, these negatively impact the ability of the claimant with ME/CFS to gain recognition that they are disabled. These problems include:

1. The standard FCE is not a valid predictor of the ability of the claimant with ME/CFS to work because it only observes the claimant doing modest degrees of exercise. There is no evidence in peer reviewed medical journals that the standard FCE can accurately predict whether a person with ME/CFS can function effectively at a full-time job.
 2. The currently used method of scoring an FCE is strongly biased to under-estimate the functional limitations that affect most persons with ME/CFS. This is because the current FCE rules forbid any gathering of information that occurred after the test and thus fails to account for the impact of post-exertional malaise on a claimant's level of day-to-day functioning.
 3. The examiner may wrongly attribute the claimant's failure to continue an assigned exercise to willful choice, not an inability to do so. For instance, if the claimant is unable to continue the test because of pain, fatigue, orthostatic intolerance or other issues, examiners may dismiss these issues and conclude the patient is deliberately "self-limiting" their behavior. This could serve as an excuse to deny or terminate benefits.
 4. The exertions during the FCE will often trigger an exceptionally severe and prolonged increase of symptoms. Given that FCE protocols do not include active surveillance of PEM, it doesn't make sense to risk having a severe episode of PEM.
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FUNCTIONAL INTERVIEWING

- Semi-structured interview in which “claimants were asked to identify at what level they would be able to maximally perform each activity (ie, lifting or carrying [kg], bending or standing [min]), and this was synthesized into an overall functional work level as with the FCE.”
- Those undergoing FCE had a higher baseline of functional work levels, but not improved RTW rates or functional work level than those who had an FI

PATIENT REPORTED OUTCOME MEASURES

- Pre-print by a group working in the field of Long COVID showed that Patient Reported Outcomes aligned with laboratory testing indicating presence of Long COVID
 - 94% accuracy at predicting Long Covid

Klein J, Wood J, Jaycox J, et al. Distinguishing features of Long COVID identified through immune profiling. medRxiv 2022.08.09.22278592;

SAMPLE PRO'S

- 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

*These outcome measures are hyperlinked on the Return to Work document provided by Realize: <https://www.realizecanada.org/wp-content/uploads/Recommendations-for-RtW-Doc-1.pdf>

Recommendations for Employers, Insurers, Human Resource Personnel and Rehabilitation Professionals on Return to Work for People Living with Long COVID

September 2022





DISCUSSION

What outcome measures are you using?

How can we better support our clients through disability claims?