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## Understanding long COVID-19: diagnosis and management

10:10 am

# LONG COVID (PACS) – IMMUNISATION COALITION PRIMARY CARE

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SACRED HEART  
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# Disclosures

- No honoraria
- Collaborated in research funded by NSW and Federal Governments  
SIRA/MAA, Ipsen and Philanthropic funders
- \* Author of a book on long COVID published and funded by Murdoch Press

# The pathway to a definition

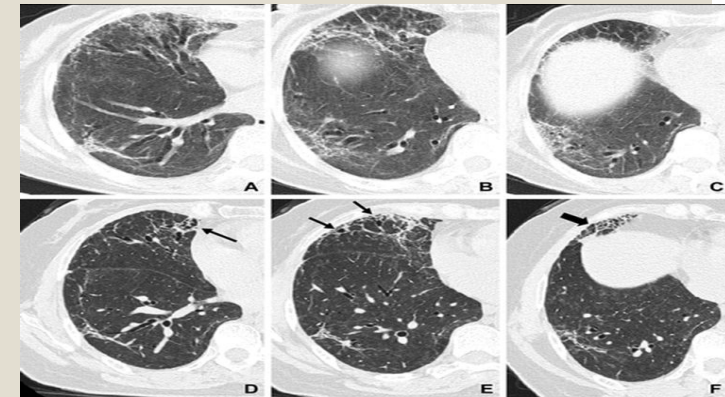
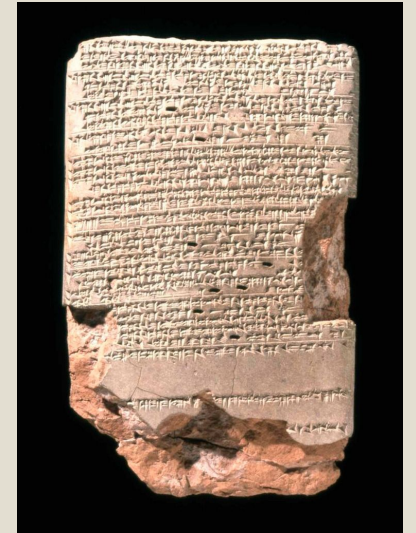
- First mention of the long haulers – Dr Perego on twitter May 2020 (Perergo E et al BMJ Oct 2020)
- British (NICE), American (NIH) and WHO definitions
- Post acute sequelae of COVID PASC 2020 – Covered those with persisting symptoms after hospitalisation but acknowledged that those out of hospital could have persistent symptoms
- Then Long COVID/PASC case definition WHO definition Oct 2021 – defined it as a diagnosis of exclusion
- Then in September 2022 Post COVID -19 condition (Long COVID) –WHO Definition – added assumed rate of 10 -20%

# Diagnostic criteria WHO defn

- Pt must have had Covid or probable Covid
  - PCR RAT
  - Neucleopcapsid antibody (infection) spike protein (Immunisation)
- Pt Must have symptoms persisting for 3 months
  - If fluctuating at least for 2 months
- There can be no other diagnostic explanation for the symptoms
  - Older patients with degenerative condition
  - Pre-existing fatigue conditions

# Is it real or is it simply another post viral syndrome?

- The history of Epilepsy (evil, 1935 Dx = stigma)
- The Spanish flu was before chronic illness and social media
- TB Polio HIV
- Should clinicians be lumpers or splitters
- The virus is different (corona viruses SAARs MERS and C19)
- There are a number of symptoms that sufferers have in common
  - Breathlessness/Cough/chest pain/ CT abnormalities
  - Fatigue cognitive impairment aguesia and anosmia
  - Mental health
  - Dysautonomia



# The Queensland research

- Compared Covid infected population n=2399 to Influenza infected population n = 995
- Found that 3.6% of Covid patients and 3.0% of those with influenza had functional impairment at 12 months
- But
  - Covid pop was >90% vac and influenza 40% vac
  - No one hospitalised/ICU was included
  - The volume of people not considered 3.6% of 3m = 144,000 vs <2500 flu



Brown M, Gerrard J, Sparrow T Andrews R (March 12 2024 – conference Abstract)  
Long Covid looks like other post viral syndromes 12 months after infection

Based on  
BMJ Public March 2023 Ongoing symptoms and functional impairment 12 weeks after testing positive for SARS-CoV-2 or influenza in Australia: an observational cohort study Matthew Brown , John Gerrard, Lynne McKinlay, John Marques, Teneika Sparrow, Ross Andrews

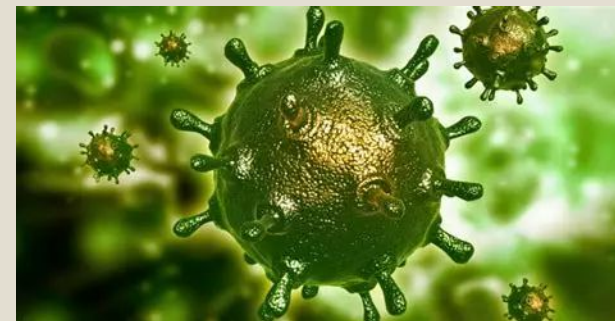


# Is it different to other illness characterised by fatigue?

- **Dyspnoea as a hallmark**
- **Radiological changes**
- **? Blood markers CRP>5**
- Bed rest comorbidities obesity
- **? Steroids, antivirals,**
- **PTSD and mental health**
- Robineau et al JAMA Nov 9 2022

n= 35000 France **89.9% had no symptoms at 2 yrs**

- **SARS:** fatigue persists for 4 years (Lam et al Arch Int Med 2009)
- Women and those using steroids associated with fatigue and weakness (Tsai et al Arch Neuro 2004)
- Lung diffusion abnormalities lasted 12 months (Tansey et al Arch Int Med 2007)
- **MERS:** persistent Lung changes for 12 months (Il Juin et al Open Forum Inf Dis 2017)





# Context of the chronic phase of epidemics

- 1920's Polio – isolation, devices (iron lung), birth of Rehabilitation (Sr Kenny – Howard Rusk) and Post Polio/Late changes
- TB – isolation, ventilation, cough etiquette, rehabilitation teams (Sanatoria) and now TB clinics and outbreaks
- HIV – protection (public health), testing , monitoring, AIDS related Complex, palliative care then rehabilitation, antivirals and community teams – now we have HAND and chronic HIV neurological illnesses
- COVID – protection public health, testing, isolation, vaccination, ventilation, PICS, Now we have Long COVID....can it be different?

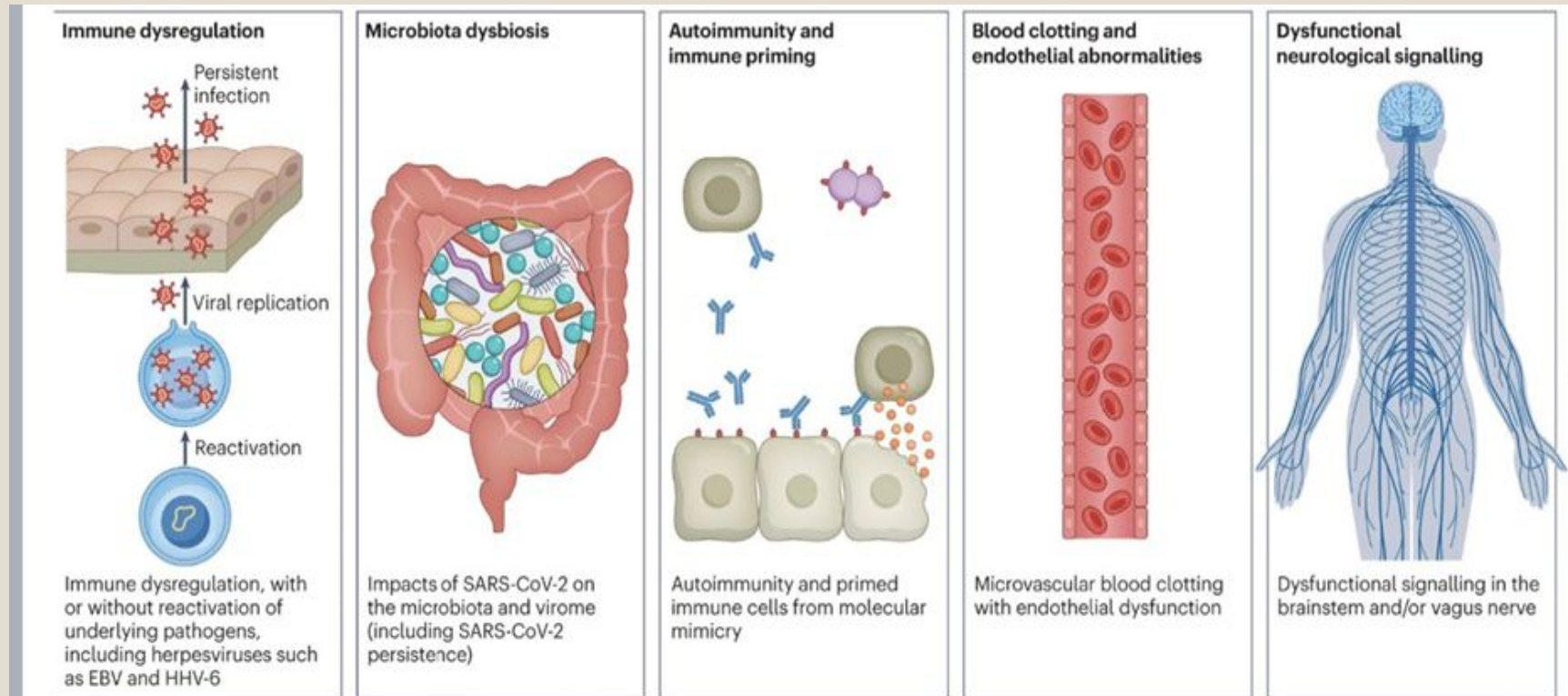


# The first step is validation

- Validation is important for the therapeutic alliance
- People do not want to give up work or stay in bed – they want their lives back
- You take them as you find them – people with mental illness and complex social situation and vulnerable personalities have all been exposed to the pandemic, lockdowns and risk of death. The chronic phase will be different for all
- Dismissing or minimising symptoms is remembered
- Somataform disorders do not occur in a vacuum

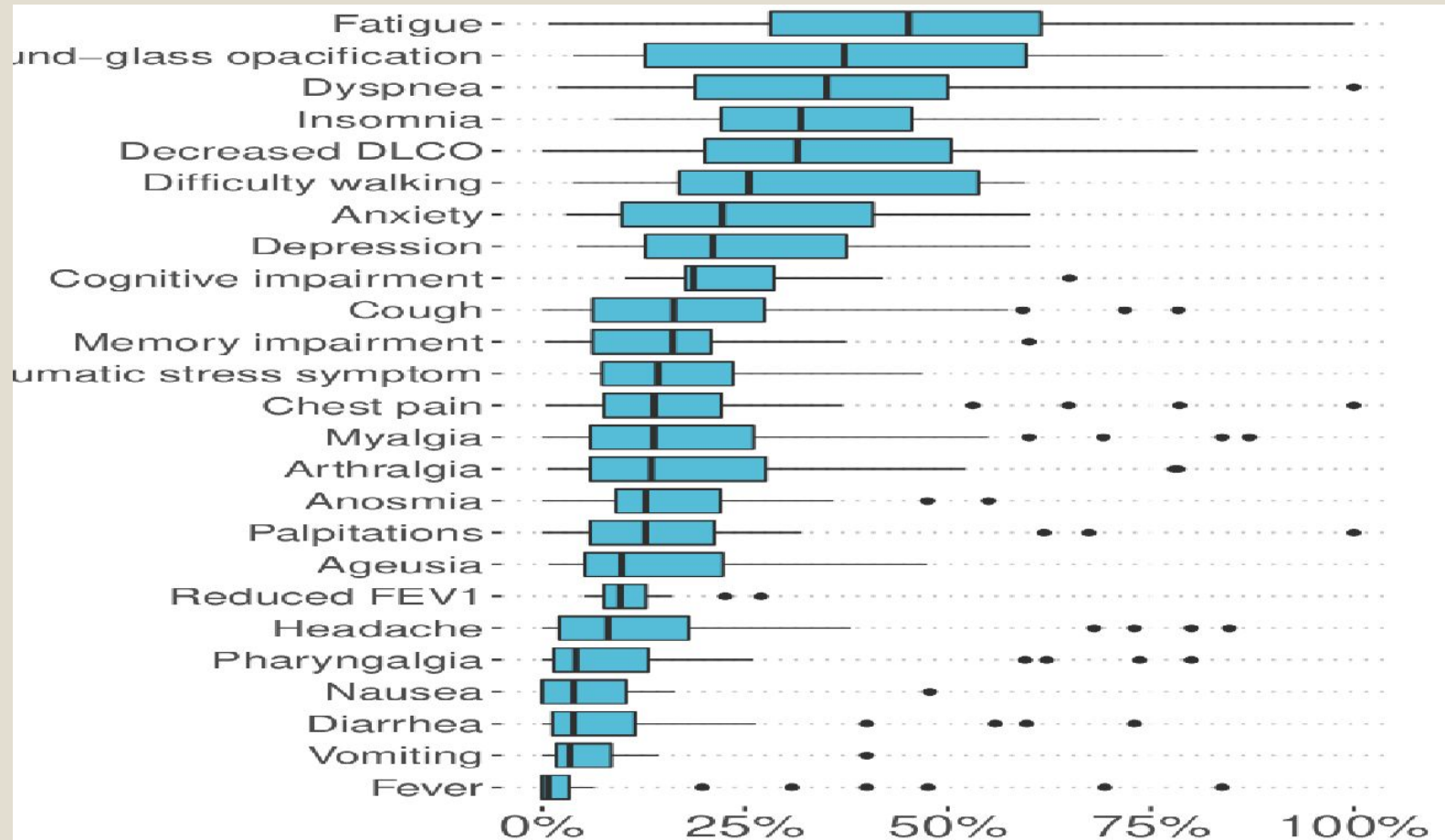


# Managing pain – a refresher on theories of mechanism



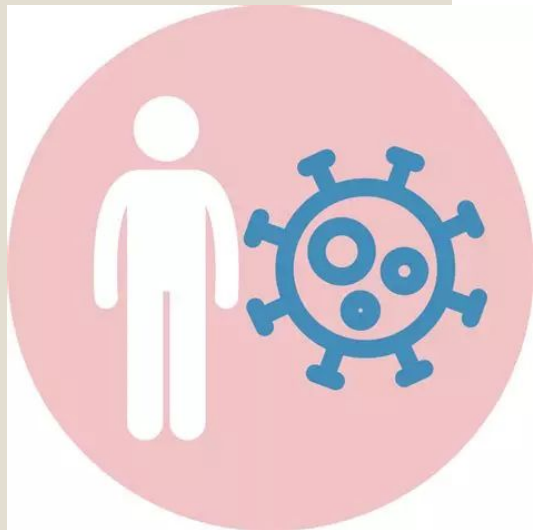
Wong et al  
Nature Oct.  
2023  
LC  
associated  
with reduced  
serotonin due  
to poor  
tryptophan  
uptake in gut

# >200 Common Symptoms for LONG COVID



**Figure 2.** Reported frequencies for the 25 phenotypic features identified in 12 or more cohorts. Box plots are shown for each item, displaying the minimum (1.5 times the interquartile range below the lower quartile), first quartile, median, third quartile, and maximum (1.5 times the interquartile range above the upper quartile). Outliers are shown as dots. DLCO: diffusing capacity of the lungs for carbon monoxide, FEV1: forced expiratory volume in one second; TLC: total lung capacity.

Deer et al Lancet 29/6 syst review characterising Long COVID MedRxiv,  
Natarajan et al May 2023 Syst Rev.



Yorkshire C19  
available on  
NSW Health's  
HOPE platform

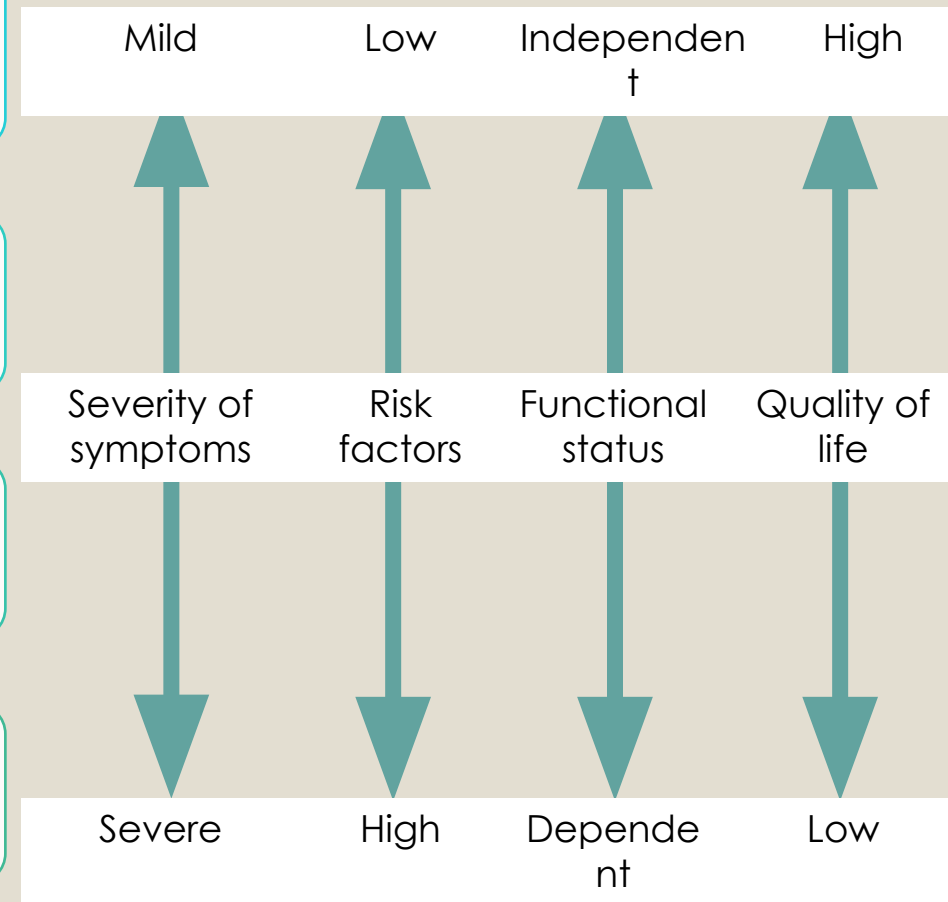
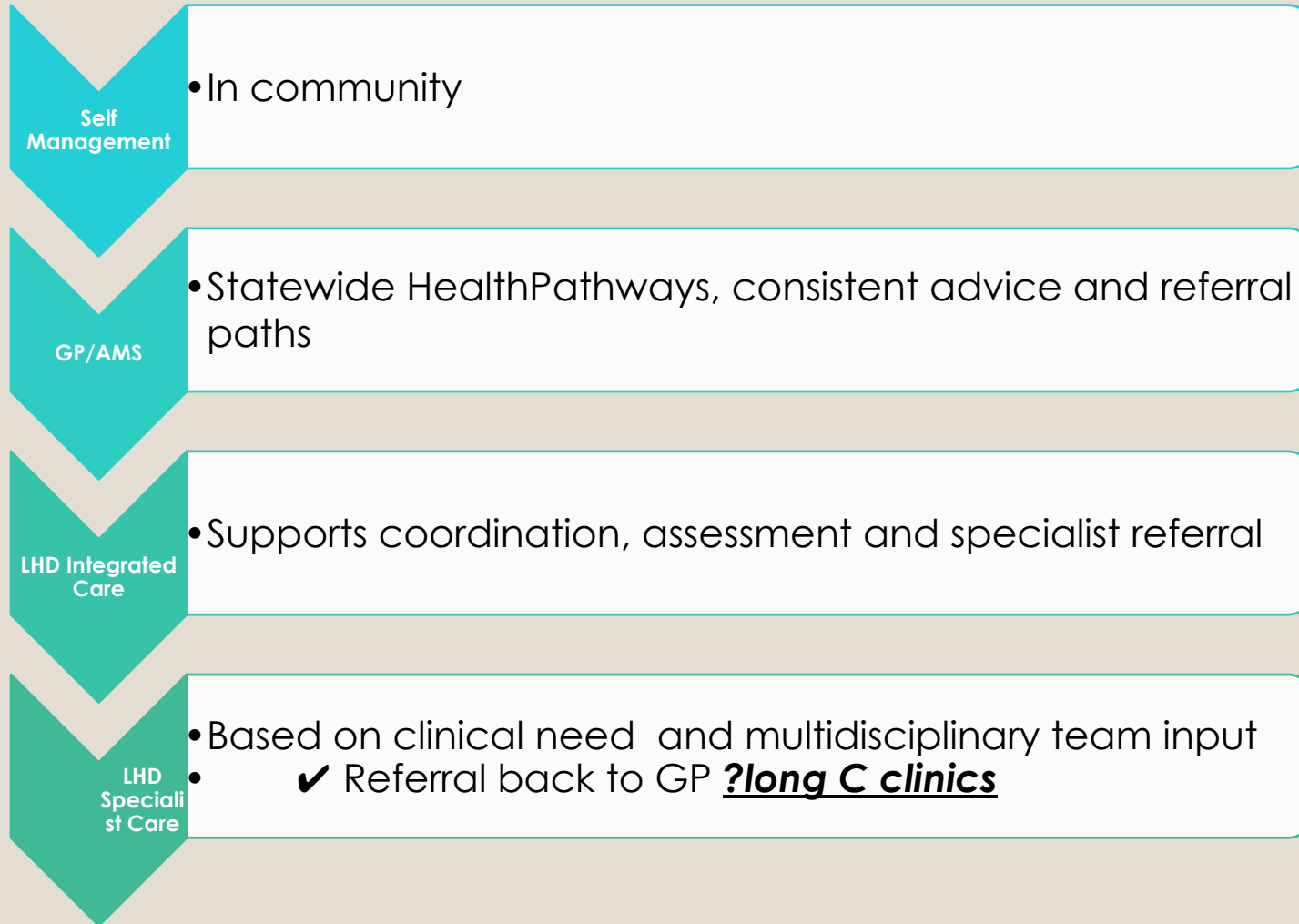
### Breakdown

	Before COVID	Now	Total Score
<b>Symptom severity</b>			
1. Breathlessness	0	6	39/100
2. Cough / Voice Change / Noisy Breathing	0	0	
3. Swallowing / Nutrition	0	0	
4. Fatigue	0	9	
5. Continence	0	0	
6. Pain / Discomfort	2	5	
7. Cognition	0	6	
8. Anxiety	2	4	
9. Depression	1	7	
10. PTSD Screen	0	2	
<b>Functional disability</b>			
11. Communication	0	4	25/50
12. Mobility	0	3	
13. Personal-Care	0	4	
14. Other activities of daily living	0	6	
15. Social Role	0	8	
<b>Overall health</b>			
16. Overall Health	8	3	3/10
<b>Other Symptoms</b>			
Rate the severity of any Dizziness you've encountered	-	6	
Rate the severity of any Palpitations you've encountered	-	7	
Rate the severity of any Weakness you've encountered	-	2	
Rate the severity of any Sleep Problems you've encountered	-	7	
Rate the severity of any Fevers you've encountered	-	0	
Rate the severity of any Skin Rash you've encountered	-	0	

### Overview

	Before COVID	Now	
<b>Symptom severity (out of 100)</b>	5	39	
<b>Functional disability (out of 50)</b>	0	25	
<b>Overall health (out of 10)</b>	8	3	

# Model of Care





# Early multidisciplinary Rehabilitation can prevent chronicity and improve outcomes

- Early supported discharge schemes in stroke show improved independence **with rehab** and decreased institutionalisation (Langhorne et al 2017)
- In reach rehabilitation in inpatient geriatrics, post - ICU, TBI and SCI and Trauma lead to improved outcomes and length of stay (Wu et al 2022)
- Home based rehab for deconditioning and frailty show improved clinical outcomes , independence and hospital admission prevention. (Lam et al Medicine Today Nov 2023)



# Evidence for early rehab in LC

- In Systematic review of early rehab for LC – (variable methodology) breathlessness, mobility, quality of life , muscle strength seemed to improve and kinesophobia declined. (Fugazzaro et al 2022)
- In a Norwegian study those with LC for 10 months who did a 3 day intensive rehab program with a telephone follow up of a home based self administered rehab program. At 3 months there were significant improvements in fatigue, breathlessness, and independence (Frisk et al Nature 2023)
- We know prolonged bed rest can be dangerous (Parker et al 2008, Lam et al 2022)



# Multidisciplinary rehabilitation in the community – processes

- Assemble your team based on the symptoms – PT, OT, Psych etc
- Have an initial case conference (health pathways) and set goals
- Commence the multidisciplinary rehabilitation
- Have a review case conference after 6-8 weeks and review attainment of goals
- Review patient at 12 weeks to complete program and assist in return to work or driving etc


# An overall plan

- Advice on further testing/vaccination/cardiovascular risk
- Measure all symptoms at the start
- A Plan for treatment
  - Physical – movement programs with physio
  - Psychological – advice re need for pacing skills
  - Occupational – advise re return to work and contact with work
  - Follow up and further outcome measurements
    - Borg Scale Physical
    - Yorkshire thought he HOPE platform
    - Fatigue severity scale



# Primary Care – referrals to rehabilitation medicine for post-COVID management

- Healthpathway documents were prepared to assist GPs managing Long COVID in the community with support from Dr Louise Delaney (Clinical Lead Advice and Support, HealthPathways Community & GP Clinical Editor HealthPathways Illawarra Shoalhaven) <https://www.health.nsw.gov.au/Infectious/covid-19/communities-of-practice/Documents/guide-multidisciplinary-public.pdf>
- The principles of referral for multidisciplinary rehabilitation by public health physicians and those seeing patients in virtual clinics were also developed
- [https://aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0018/616104/ACI-Rehab-Comms-Referral-Processes-Virtual-Care-Clinics-Services.pdf](https://aci.health.nsw.gov.au/_data/assets/pdf_file/0018/616104/ACI-Rehab-Comms-Referral-Processes-Virtual-Care-Clinics-Services.pdf)
- A model of care document is currently being revised for the management of adults with COVID-19 in the post acute phase to update the current document
- [Management of adults with COVID-19 in the post-acute phase – A model of care for NSW health clinicians](#)



## HealthPathways

Prescription for rehabilitation

Prescription for rehab

Date completed:

*Prescription for Rehabilitation*

Patient name: Date of birth: Address:	Date of onset COVID-19 illness: Swab dates: Hospital Admission dates: ICU admission dates:	
Medicare No: GP: GP contact No:		
<p><b>Your Rehabilitation Prescription:</b>  <b>Rehabilitation care coordinator (NB: Practice nurse may act as care coordinator as part of their role)</b></p>		
Daily activities:		
Services referred to:	Contact details	Appointment dates
<p>Current goals: below is a table that should be put her and some sample goals for one symptom (ie fatigue) and explanations in italics</p>		

nsw.health.nsw.gov.au

## Multidisciplinary rehabilitation communication and referral

for patients diagnosed with, or recovering from COVID-19

**Information for public health physicians and their teams, general practitioners and primary health teams**

This document provides guidance on referring people who have recovered from COVID-19 and are experiencing ongoing symptoms, to multidisciplinary rehabilitation assessment and management.

**The long tail of COVID-19**

Research on COVID-19 has revealed that up to 10% of people who have recovered from COVID-19 continue to suffer from long-term symptoms, known as long COVID. These symptoms can include fatigue, breathlessness, chest pain, muscle pain, memory and concentration problems, and more.

These ongoing symptoms are sometimes referred to as the long tail of COVID. The most commonly reported symptoms are fatigue, breathlessness, chest pain, muscle pain, memory and concentration problems, and more.

Further advice on living with ongoing effects of COVID-19, along with people who rely on regular health care for rehabilitation services in the community are suffering functional decline should be sought from a GP or other health professional.

NSW Health logo and logo for the Department of Health and Human Services.

# What doesn't work and therapeutic trials

- TENs, TMS and VR are being promoted but there is little evidence. Trials are ongoing (Thams et al 2022 BMJ protocol paper)
- PEA (Palmitoylethanolamide), omega 3 fatty acids, Vitamins B1, B6, B12, C, D Mg, Co-enzyme Q10, Echinacea, Ginseng, Turmeric. Have little or no evidence but are low risk (Raciti et al hypothesis paper 2022)
- Hyperbaric Oxygen – no protocols available as yet ( Paganini et al 2020)
- Off label medications include monofanil, antidepressants, stimulants, L-Dopa again with very low evidence – trials are commencing in the US
- **Off label use needs to be carefully considered, risks v benefits, costs v benefits, consent of patient, liability (MDO) for complications, the use of an experimental design with an outcome measure and ABA pattern in an N on 1 trial is advised**

# N on one trials of medications

- You are responsible and need to annotate that this is part of a trial
- Consent for use in a trial setting?
- Is it safe? Is it expensive? (Bond University dept GP)
- Decide on an outcome measure? Fatigue severity Scale
- ABA pattern – on –off –on again
- Test before and after each stage with your outcome measure
- At end of the nine weeks look at the results
- And then make a decision - re cost – benefit and effect size

# Case study – Stephanie 59 year old real estate agent

- Covid Jan 2022 Phi Myasthenia gravis treated with Thymectomy
- Fatigue cough breathlessness anosmia brain fog, initially but Now.....
- Slow at work, errors, tingling in face and occasional foot drop, distressed
- MRI NAD & MOCA 24/30
- Fatigue and exc intolerance – started resistance program
- Palpitations felt when very fatigued

Would you

- a) Commence rehabilitation with a graded exercise program
- b) Exclude cardiomyopathy with an echo and holter and tfts
- c) Commence treatment for anxiety
- d) Check MUSK antibodies and acetylcholinesterase antibodies
- e) Commence a rehabilitation program with pacing and cognitive retraining and a tailored movement /activity program
- f) All of the above except a.



# Case study

- Answer D
- Admitted for tilt tabling and cardia mri/echo to exclude myopathy and pulm hypertension
- **Musk and anti C antibodies were high and different to levels done before covid**
- commenced mastinon
- commenced a pacing program with a psychologist and an activity program with a physio
- Returned to work within 6 weeks part time

# Vaccination may decrease your risk of Long Covid.

## If you have long Covid vaccination may improve or have no effect on LC symptoms

- Impact of vaccination on long COVID are mixed (Han et al 2022).
- Vaccinated has no impact on contracting all symptoms of long COVID ( Taquet et al 2022) while Al-Aly et al says a 15% reduction in the incidence of long COVID of those vaccinated (Al-Aly et al 2022).
- Methodologies vary – so the results are not rock solid.
- In a UK study of those looking at those who were vaccinated, 9.5% contracted long COVID while 14.6% of those unvaccinated were affected by long COVID (Ayoubhani et al 2022).
- Vaccination for those with long COVID – most have no change in symptoms and 16% the symptoms can improve.
- 21% of cases, the symptoms of long COVID may worsen as the post vaccination response likely associated with an over active immune response to vaccination (Tsuchida et al 2022).
- Contracting COVID also offers immunity 6 months

# The use of antivirals to prevent hospitalisation and risk of death

- Severe illness or hospitalisation is a risk factor for long COVID
- Over 70, over 50 with risk factors, first nations over 30
- Paxlovid has been shown to decrease risks with the delta strain and omicron to a lesser extent
- For those who can't take Paxlovid, Molnupavir may help those non hospitalised (mild disease)
- Remdesivir may prevent hospitalisation but it often only used in hospital as it is an infusion (costly). It may be available to high risk patients who are unsuitable for other forms of antiV
- Nirmatrelvir in one study was shown to decrease the rate of long COVID
- For those not suitable (immune disorders or transplants) monoclonal antibodies can be considered



# Save the Date

1-6 June 2024

Thanks and any Questions?



📍 Sydney, Australia

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