Webinar 1
ME/CFS & long COVID: An evidence-based guide for General Practitioners

Assessment and Diagnosis

Dr Mark Donohoe

Proudly supported by the John James Foundation.

Acknowledgement of Country

Emerge Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land on which we operate.

We pay our respect to the ongoing living cultures of Aboriginal peoples, and to Elders past and present and emerging.

Housekeeping

- 60 minutes for presentation
- 20 minutes for questions
- If you wish to put questions in the chat thread, please do so at any time We will ask them during question time
- Webinars are recorded. Cameras and mics have been muted
- RACGP members will have their CPD uploaded within a week
- ME/CFS and long COVID aware GP directory

Learning outcomes

1. Understand the terms ME/CFS, PASC & long COVID
2. Explore presenting signs and symptoms including ordering appropriate investigations
3. Apply diagnostic criteria to patient data, to positively identify a case of ME/CFS or long COVID
4. Communicate findings from history, physical examination and investigations to a patient and their carers

An important consideration is that ME/CFS and long COVID are not simple single diseases. They are multi-organ and multiple contribution illnesses that sometimes require detective work to see why the person has become sick and persisted with their illness over time.

Commonly, there are:

- Multiple contributions, predispositions and triggers
- Unique history and findings

This can challenge our normal medical diagnostic paradigm

Neither is a simple disease

- Consensus emerging of multi-system complex illness
- No specialty in Medicine covers the full range
- Falls on GPs and primary healthcare providers
- Identifying causes, contributions and exacerbating factors is important and time-consuming
- Symptom management, ongoing support and care is critical
- Social justice and disability management is important

There are things you can do

- Illness trajectory is uncertain
- There is no magic treatment

BUT

You can:

- Support them
- Believe them
- Help them with their symptoms to improve their quality of life
- Identify and care for other conditions as they arise

Definitions: ME/CFS

- "ME/CFS is a **serious, chronic, complex and multisystem disease** that frequently and dramatically limits the activities of affected patients"

(NAM, 2015)

- ICD code G93.32

(CDC, 2024)

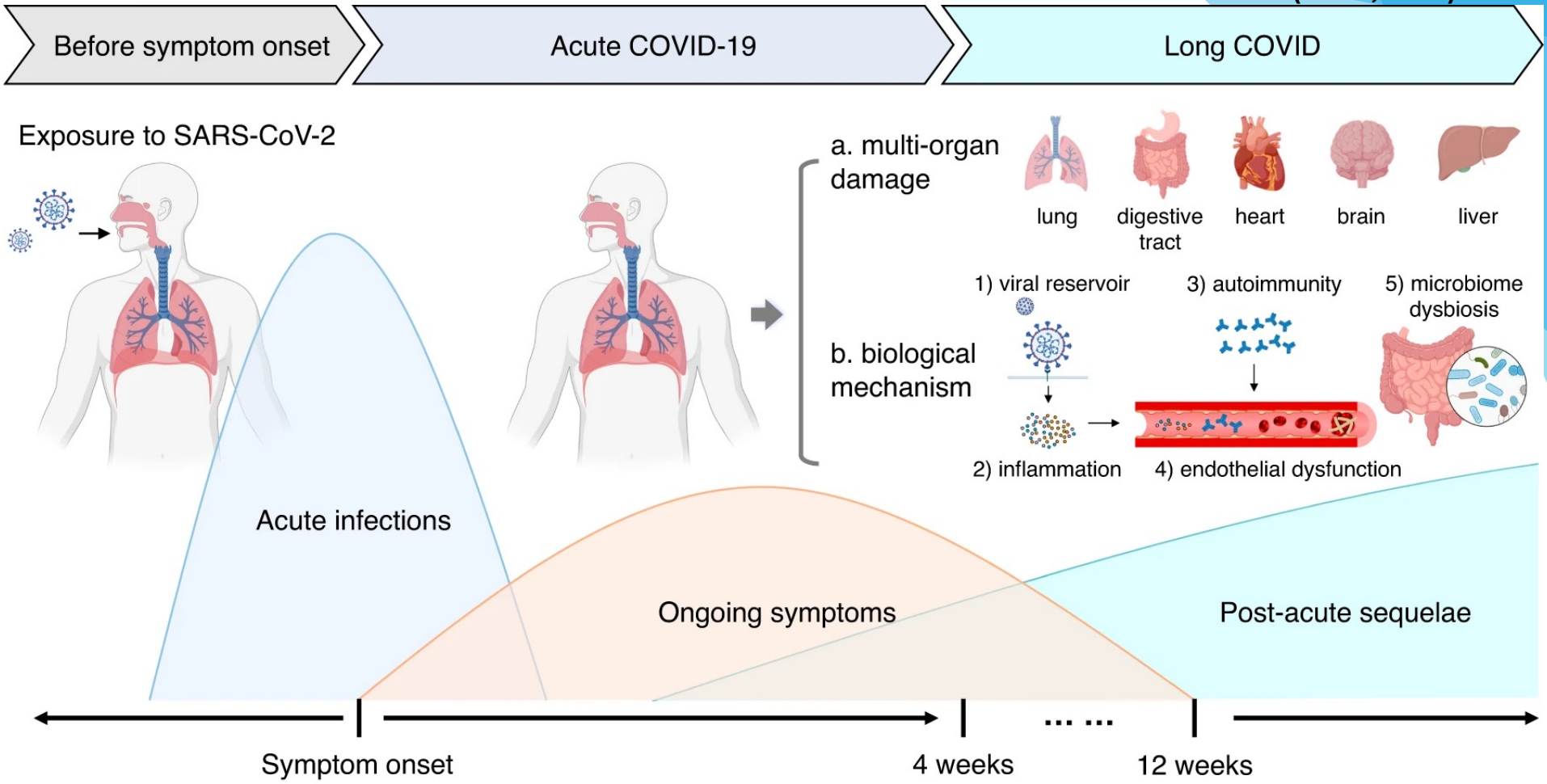
ME/CFS affects:

- 0.4 - 1% of the population but **90% undiagnosed**
- Low recovery rate overall
- Higher recovery rate in first two years
- 75% women
- Any age
- 45% -50% of people with long COVID meet diagnostic criteria for ME/CFS (Nam, 2015; Dehlia & Guthridge, 2024; Kedor, 2022)

Definitions: “long COVID”

International Classification of Diseases-10 code: U09.9

(WHO, 2024)



https://www.nature.com/articles/s41392-023-01640-z/figures/1

(Li et al, 2023)

What leads to ME/CFS & long COVID?

ME/CFS

- Multiple potential triggers – infections, trauma, environmental exposures
- Heritability? More common MZ twins, EDS
- Definable onset: 80%
- Undefinable onset: 20%

Long COVID?

- Severity of acute infection - ICU
- Multiple COVID-19 infections or poor response to vaccination
- Female sex
- ?Age
- Existing conditions

(Bateman et al, 2021; Griffin 2023)

Can we prevent ME/CFS and long COVID?

ME/CFS???

Long COVID:

- Antivirals
- Vaccination
- Healthy Lifestyle?
- Control of comorbidities
- Careful return to activity post-infection

Common factors between ME/CFS & long COVID

History

- typically a definable infection e.g. EBV, mycoplasma, rickettsia, CMV, influenza, COVID-19

Timeline

- incomplete recovery from acute infection OR

- period of full recovery between infection and relapse

Shared symptoms

- fatigue, post-exertional malaise, sleep disorder and light-headedness on standing or POTS-like symptoms

Diagnostic Criteria: ME/CFS

National Academy of Medicine Clinical Diagnostic Criteria (NAM, 2015)

Symptoms at least half of the time with moderate, substantial, or severe intensity			
Impaired function in association with fatigue/low stamina > 6 months	PEM: Post-exertional malaise (illness gets worse after minimal activity)	Unrefreshing sleep	Cognitive impairment and/or Orthostatic intolerance

Symptom screen – ME/CFS

Can be used as:

- Initial symptom screen. Can do one in PEM and one at "baseline"
- Shared decision making
- Long term monitoring

SYMPTOM SEVERITY AND SEVERITY HIERARCHY PROFILE

Adapted from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document. Carruthers BM, van de Sande MI.

Name _____ **Date from** ____/____/____

Instructions:

1. Rank your symptoms in order of severity (1 being your most severe symptom) in the left column.
2. Rate severity of symptoms by putting a check mark in the appropriate column to the right of symptoms.

Symptom severity and Severity hierarchy profile					
Rank	Symptom	Absent (0)	Mild (1)	Moderate (2)	Severe (3)
	Post-exertional fatigue: loss of physical and mental stamina, fatigue made worse by physical exertion				
	Long recovery period from exertion: takes more than 24 hours to recover to pre-exertion activity level				
	Fatigue: persistent, marked fatigue that substantially reduces activity level				
	Sleep disturbance: non-restorative sleep, insomnia, hypersomnia				
	Pain: in muscles, joints, headaches				
	Memory disturbance: poor short term memory				
	Confusion and difficulty concentrating				
	Difficulty retrieving words or saying the wrong word				
	Gastrointestinal disturbance: diarrhoea, IBS				
	Recurrent sore throat				
	Recurrent flu-like symptoms				
	Dizziness or weakness upon standing				
	Change in body temperature, erratic body temperature, cold hands and feet				
	Heat/cold intolerance				
	Hot flushes, sweating episodes				
	Marked weight change				
	Breathless with exertion				
	Tender lymph nodes: especially at sides of neck and under arms				
	Sensitive to light, noise, or odours				
	Muscle weakness				
	New sensitivities to food/medications/chemicals				
	Total check marks in column	x0	x1	x2	x3
	Column total				

Total score: _____ **Overall symptom severity:** _____ **mild,** _____ **moderate,** _____ **severe**

Other symptoms _____

Aggravators _____

Change in symptoms _____

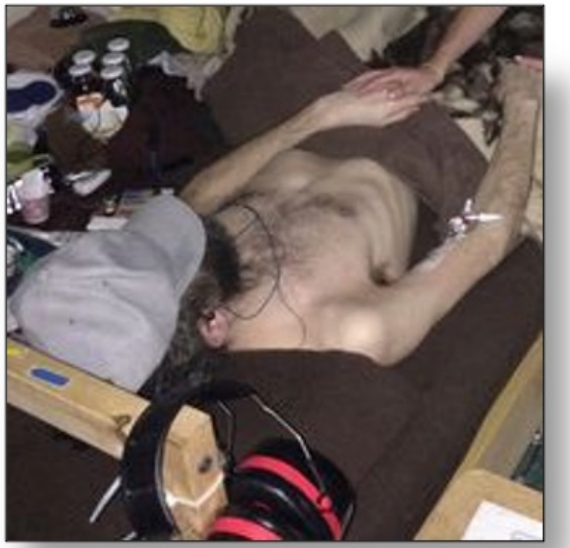
How good is your sleep on a scale of 1 to 5? (5 = good restorative sleep, 1 = no sleep) _____

How do you feel today on a scale of 1 to 10? (10 = terrific, 1 = totally bedridden) _____

They look fine but.....

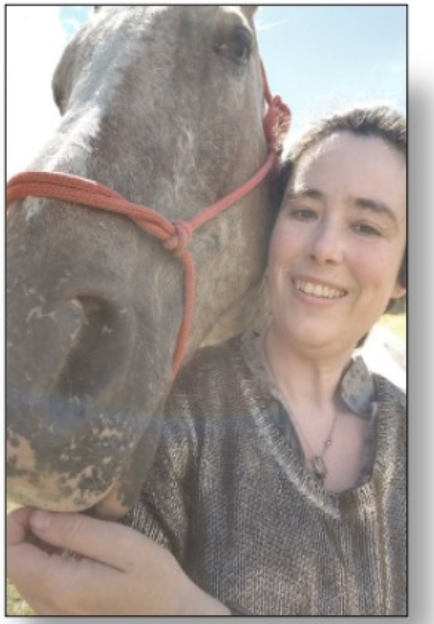
How they present does not necessarily reflect how they are

(Montoya et al, 2021)



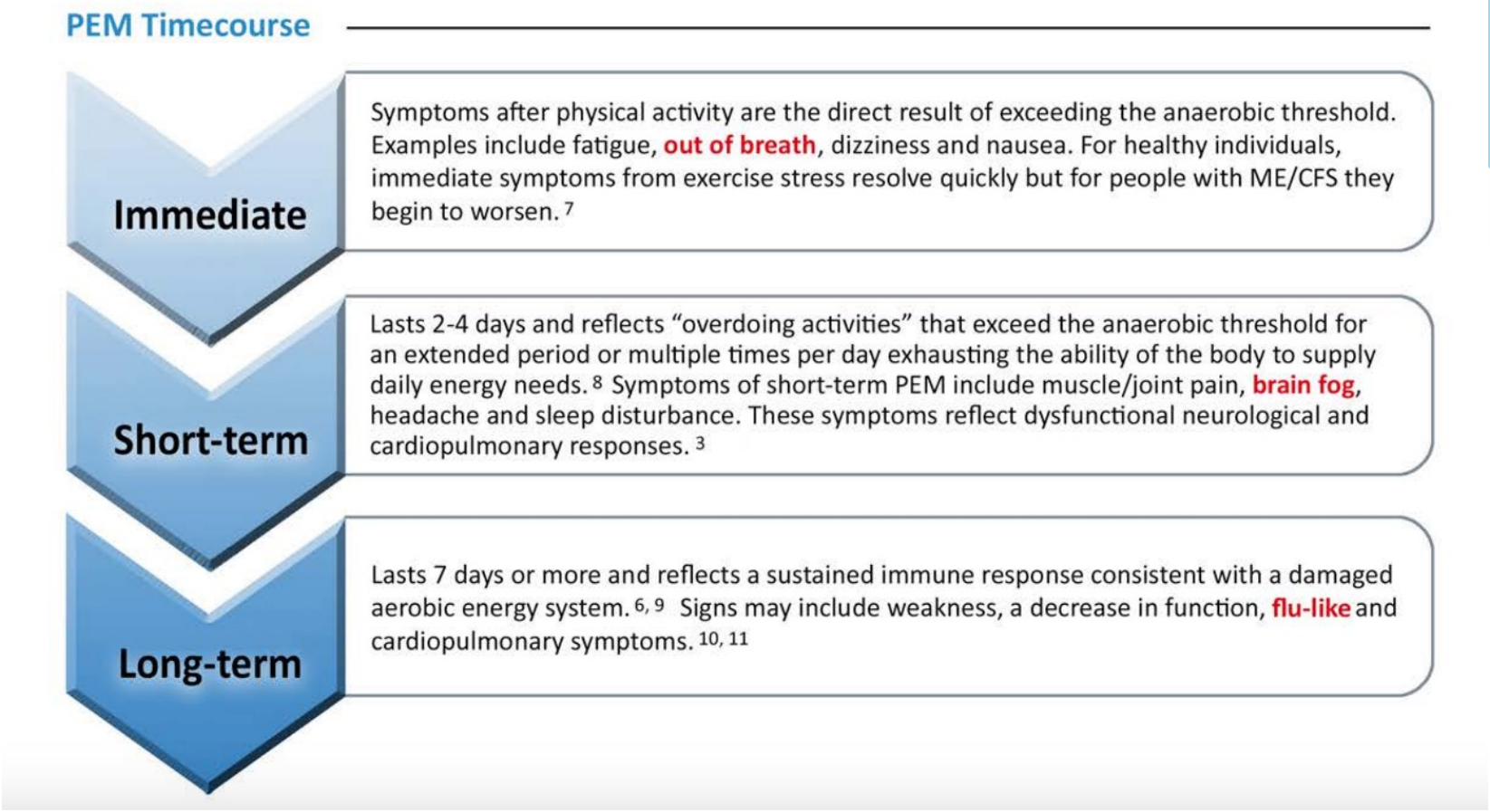
(https://www.facebook.com/whitneydafoe/photos)

(personal communication, with permission)



(personal communication with permission)

Post-exertional malaise (PEM)



(Workwell Foundation, 2022. https://workwellfoundation.org/wp-content/uploads/2023/01/WW-PEM-Timecourse.pdf)

Diagnostic approach: “long COVID”

- Break down into categories
- Be mindful of crossover with ME/CFS
- Identify dysautonomias
  - There are clear management programs here for reducing disability
- Other proposed mechanisms and pathological processes
  - Autoimmune processes – “spikeopathy” and molecular mimicry
  - Coinfection (EBV, CMV, HHV6, mycoplasma, rickettsia etc)
  - Persisting SARS-CoV-2 infection (Gut is of interest)
  - Coagulopathy (microclots, vascular issues)
  - Mitochondrial and metabolic dysfunction (muscle, cognition)
  - MCAS

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ACNEM

diagnostic tools – Long COVID (in validation)

acnem **Client Data Entry Form v 5.1 beta**

ID			
Date of Questionnaire	21/07/23	Illness following what?	COVID-19 Infection
Subject ID (optional)	SX	Date of first symptoms	15/06/22
Subject Name (optional)	Sally X	Most recent vaccine	Unknown
Gender (optional)	Female	Duration	57w 2d
Month/year of Birth	March 1981		
Calculated Age	43	Practitioner Name	Dr Mark Donohoe
		Practitioner ID	MD007
CONTACT PREFERENCES			
Yes, you can contact me	☐	Preferred contact method	Email
I have read the data privacy info	☐	Contact details	

acnem Long COVID Symptom Checklist v 5.1 beta

#	SYMPTOMS - check for new symptoms If present, check the box in next column. This is only for symptoms arising subsequent to the infection or vaccination causing your current condition	Currently suffering?
1	Fatigue	☐
2	Shortness of breath	☐
3	Cognitive dysfunction / Brain fog	☐
4	Post-exertional malaise	☐
5	Abnormal movement	☐
6	Muscle spasms	☐
7	Cough	☐
8	Sleep disorder	☐
9	Tachycardia/heart palpitations	☐
10	Changes to taste and smell	☐
11	Headache	☐
12	Chest pain	☐
13	Joint pain	☐
14	Depression	☐
15	Anxiety	☐
16	Neuralgia	☐
17	Dizziness	☐
18	Fever	☐
19	Tinnitus	☐
20	Paraesthesia/Pins and needles	☐
21	Blurred vision	☐
22	Abdominal/gastrointestinal	☐
23	New onset allergy	☐
24	Thirst	☐
25	Sexual desire/capacity	☐
26	Altered menstrual cycle	☐
27	Hair loss	☐
28	Sore throat ± tender lymph nodes	☐
29	Sensory sensitivity (light, sound, touch)	☐

NOTES

This rapid checklist does not assess severity and impact on life quality. It simply determines the diagnosis of long COVID / Post-acute sequelae of COVID-19 according to three criteria:

- The WHO 2021 criteria;
- The RECOVER consortium 2023 criteria; and
- The acnem long COVID criteria.

Symptoms are listed in the order described in the WHO diagnostic criteria for "post COVID-19 condition" (PCC), also known as "Post-acute sequelae of COVID-19" (PASC) and colloquially as "long COVID". They are numbered 1 to 24. This list was created in late 2021, before the omicron variants.

The symptoms coloured GREEN (#1,3,4,5,7,9,10,12,17,22,24,25) are those nominated by the RECOVER Consortium in the Journal of the American Medical Association (JAMA), May 2023. This is the current (as at 8/2023) proposed research definition for PASC) / long COVID. These symptoms are proposed for research classification / scoring, and can be used for that purpose. Data were collected in both pre-omicron and omicron periods. They are subject to future review and revision, and may be of limited clinical value.

The symptoms coloured BLUE (#26-29) are those additional symptoms identified by **acnem** clinicians and proposed for classification in addition to the WHO and RECOVER symptom list.

This document is the abbreviated **acnem** diagnostic checklist for diagnosis by symptom presence. It notes the highest ranked subgroup according to the **acnem** long COVID conference 2023 as the only additional data for clinicians.

The expanded **acnem** questionnaire is available and addresses clinical significance, including severity and frequency of the symptoms, disability, and adverse impact on quality of live.

Email your completed checklist to: LCDATA@acnem.org

acnem **Client Data Entry Form v 5.0 (beta)**

ID			
Date of Questionnaire		Illness following what?	
Subject ID (optional)		Date of first symptoms	
Subject Name (optional)	\	Most recent vaccine	
Gender (optional)		Duration	19/07/23
Month/year of Birth			
Calculated Age		Practitioner Name	
		Practitioner ID	
CONTACT PREFERENCES			
Yes, you can contact me	☐	Preferred contact method	Email
I have read the data privacy info	☐	Contact details	

acnem Long COVID Symptom Questionnaire v 5.0 (beta)

	SEVERITY OF IMPACT quality of life					
	Your estimate of impact	•	•	•	•	•
	Your practitioner's estimate of impact	•	•	•	•	•
	Calculated impact on life quality (calc)	☆	☆	☆	☆	☆

#	SYMPTOMS - check if new symptoms If present, check the box in next column, then score severity and frequency of that symptom in the subsequent columns for that symptom. This is only for symptoms arising subsequent to the infection or vaccination causing your current condition	Currently suffering?	Severity score 1=mild /minimal effect 2=moderately severe effect 3=severe and disabling 4=very severely disabling 5=extremely severe / disabling	Frequency score 1=at least monthly 2=at least weekly 3=at least daily 4=many times daily 5=continuous, no relief	Weight
1	Fatigue	☐	• • • • •	• • • • •	0.0
2	Shortness of breath	☐	• • • • •	• • • • •	0.0
3	Cognitive dysfunction / Brain fog	☐	• • • • •	• • • • •	0.0
4	Post-exertional malaise	☐	• • • • •	• • • • •	0.0
5	Abnormal movement	☐	• • • • •	• • • • •	0.0
6	Muscle spasms	☐	• • • • •	• • • • •	0.0
7	Cough	☐	• • • • •	• • • • •	0.0
8	Sleep disorder	☐	• • • • •	• • • • •	0.0
9	Tachycardia/heart palpitations	☐	• • • • •	• • • • •	0.0
10	Changes to taste and smell	☐	• • • • •	• • • • •	0.0
11	Headache	☐	• • • • •	• • • • •	0.0
12	Chest pain	☐	• • • • •	• • • • •	0.0
13	Joint pain	☐	• • • • •	• • • • •	0.0
14	Depression	☐	• • • • •	• • • • •	0.0
15	Anxiety	☐	• • • • •	• • • • •	0.0
16	Neuralgia	☐	• • • • •	• • • • •	0.0
17	Dizziness	☐	• • • • •	• • • • •	0.0
18	Fever	☐	• • • • •	• • • • •	0.0
19	Tinnitus	☐	• • • • •	• • • • •	0.0
20	Paraesthesia/Pins and needles	☐	• • • • •	• • • • •	0.0
21	Blurred vision	☐	• • • • •	• • • • •	0.0
22	Abdominal/gastrointestinal symptoms	☐	• • • • •	• • • • •	0.0
23	New onset allergy	☐	• • • • •	• • • • •	0.0
24	Thirst	☐	• • • • •	• • • • •	0.0
25	Sexual desire/capacity	☐	• • • • •	• • • • •	0.0
26	Altered menstruation	☐	• • • • •	• • • • •	0.0
27	Hair loss	☐	• • • • •	• • • • •	0.0
28	Sore throat and/or tender lymph nodes	☐	• • • • •	• • • • •	0.0
29	Sensory sensitivity (light, sound, touch)	☐	• • • • •	• • • • •	0.0

NOTES

Symptoms 1 to 24 are listed in the order described in the WHO diagnostic criteria for "post COVID-19 condition" (PCC), also known as "Post-acute sequelae of COVID-19" (PASC) and colloquially as "long COVID", and numbered 1 to 24. This list was created in late 2021, prior to the arrival of the omicron variant.

The symptoms coloured **GREEN** are those reported by the RECOVER Consortium in the Journal of the American Medical Association (JAMA), May 2023. This is the currently proposed research definition for Post-acute sequelae of COVID-19 (PASC) / long COVID. These symptoms are proposed for research classification / scoring, and can be used for that purpose. They are subject to future review and revision, and may be of limited clinical value.

The symptoms coloured **BLUE** (#26 to 29) are those additional symptoms identified by **acnem** clinicians and proposed for clinical assessment in addition to the WHO and RECOVER symptom list. The **acnem** diagnostic questionnaire is designed to address clinical significance, including severity and frequency of the symptoms, disability, and adverse impact on quality of live.
Email your completed questionnaire to: info@acnem.org

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Report from ACNEM questionnaire Long COVID

(In validation)

acnem **Results of long COVID Checklist** v 5.0beta

Details			
Date of Checklist	19/07/23	**Illness following what?**	**COVID-19 Infection**
Subject Name / ID	[redacted]	**Date of first symptoms**	**01/01/23**
Age	43	**Most recent vaccine**	**Unknown**
Gender	Female	**Duration of symptoms**	**28w 3d**
Practitioner	[redacted]		
Contact details		**Date of this report**	**19/7/2023**
Notes			

RESULTS USING WHO CRITERIA	
Duration of PCP / PASC / long COVID	**28w 3d**
Key Symptoms count from WHO list of 24	**11**
WHO long COVID diagnosis - RESULT	**Long Covid**

This table uses the WHO 2021 case definition of Post COVID-19 Condition (also know.n as Post-acute sequelae of COVID-19 (PASC) and long COVID) for defining cases. It is included as it was the definition proposed by the Australian Parliamentary Inquiry into Long COVID and Repeated COVID Infections (link below).

The WHO definition does not address issues of severity or frequency of symptoms or provide useful clinical information beyond the confirmation of WHO diagnosis. It was published prior to the emergence of the omicron SARS-CoV-2 variants.

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/LongandrepeatedCOVID

RESULTS USING JAMA / RECOVER CRITERIA	
Duration of long COVID / PASC	**28w 3d**
JAMA / RECOVER Score	**16**
Fulfils JAMA / RECOVER PASC criteria	**Yes**
JAMA / RECOVER PASC subgroup	**Cluster 3**

This table uses the RECOVER Consortium algorithm and criteria published in the JAMA (link below). It is a proposed research definition for Post-acute sequelae of COVID-19 / long COVID. The paper identifies twelve weighted symptoms (PEM, fatigue, brain fog, dizziness, GI symptoms, palpitations, changes in sexual desire or capacity, loss of or change in smell or taste, thirst, chronic cough, chest pain, and abnormal movements) to create a score. Any score of 12 or above is used to separate likely long COVID from other causes of the symptoms.

*In addition, the paper proposes 4 "clusters" of patient types for research purposes, as well as a . This document is **not** designed to address clinical classification, nor does it address severity or frequency of symptoms*

https://jamanetwork.com/journals/jama/fullarticle/2805540

RESULTS USING ACNEM LONG COVID CRITERIA	
Duration of long COVID	**28w 3d**
Symptom count (of 29 listed)	**11**
Fulfils long COVID diagnostic criteria	**Yes**
acnem long COVID impairment category	**Severe impairment**
Predicted category for clinical fosus	**Metabolic / Mitochondrial**

*The **acnem** criteria are based on the symptom lists common to the WHO and RECOVER Consortium criteria, with the addition of certain missing symptoms identified by **acnem** practitioners. The **acnem** checklist allows for an estimate of impact on health and disability of the sufferer, recovery or worsening over time, and an indication of the type of long COVID addressed by the **acnem** long COVID conference 2023.*

The estimates of severity and frequency of symptoms provide the practitioner and client with clinically meaningful measures for assessing progression or recovery over time and with treatment. Information gained by the questionnaire will also help inform directions for future clinical research

Symptoms: long COVID

- Fatigue lasting over 6 months in over 50%
- Post-exertional malaise (PEM) in over 70%
- Cognitive impairment documented on testing in 25-50%
- Respiratory symptoms including **dyspnoea in some** Neurological issues such as headaches, anosmia and brain fog
- Autonomic dysfunction - high proportion

(Griffin, 2024)

Emerging research ME/CFS and long & COVID

- Immune cell changes and persistent complement activation
- Gut microbiome changes - sequencing
- Mitochondrial dysfunction - gene expression studies
- Neuroinflammation and BBB disruption - MRI and animal models
- Blood flow and oxygen distribution issues

(Griffin, 2024, Komaroff & Lipkin, 2021)

The following slides relate to both ME/CFS & long COVID

- physical examination
- Investigation
- Initial management

Physical examination

Common findings:

- Tender and/or enlarged lymph nodes
- Marked light, sound or smell sensitivity or anosmia
- Dizziness / vertigo on standing
- BP drop or pulse rate rise > 30 bpm on standing
    - NASA Lean Test may be better done at home and recorded
- Joint hypermobility - Ehlers-Danlos Syndrome common

Examination: Further considerations

- Dysautonomia
- NASA lean test over 10 minutes – at home
- Sitting and standing in clinic
- 24 hour BP/HR monitors
- Note – many patients do not faint

Orthostatic Vital Signs/The NASA 10-minute Lean Test

	Blood Pressure (BP)		Pulse	Comments
	Systolic	Diastolic		
Supine 1 minute	122	85	85	Lying down
Supine 2 minute	120	80	80	Lying down
Standing 0 minute	110	73	120	
Standing 1 minute	132	90	120	
Standing 2 minute	137	90	131	Feet tingling
Standing 3 minute	120	96	131	
Standing 4 minute	135	99	150	Breathless
Standing 5 minute	130	100	162	Feeling faint. Test stopped
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				

Recommended Reading re POTS

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JACC FOCUS SEMINAR

Postural Orthostatic Tachycardia Syndrome

JACC Focus Seminar

Meredith Bryarly, MD,[a,*] Lauren T. Phillips, MD,[a,*] Qi Fu, MD, PhD,[b,c] Steven Vernino, MD, PhD,[a] Benjamin D. Levine, MD[b,c]

ABSTRACT

Postural orthostatic tachycardia syndrome (POTS), the most common form of orthostatic intolerance in young people, affects approximately 500,000 people in the United States alone, typically young women at the peak of their education and the beginning of their working lives. This is a heterogeneous disorder, the pathophysiology and mechanisms of which are not well understood. There are multiple contributing factors and numerous potential mimics. This review details the most current views on the potential causes, comorbid conditions, proposed subtypes, differential diagnoses, evaluations, and treatment of POTS from cardiological and neurological perspectives. (J Am Coll Cardiol 2019;73:1207–28)
© 2019 by the American College of Cardiology Foundation.

Postural orthostatic tachycardia syndrome isolated orthostatic intolerance, which is a broader

Look at past results

- Look at the trends not just ranges

- Take time to save time

- Timelines for onset of symptoms

- Can guide further testing

Investigations – ME/CFS & long COVID

Primary testing

- Full blood examination
- c-reactive protein,
- anti-nuclear antibody,
- Full biochemistry with liver function and kidney function
- nutrition such as B12, zinc, folate, vitamin D, and iron
- Urinalysis – albumin/creat
- EBV, HH6 & CMV - IgM

Consider

- RF, anti-CCP
- 9 am cortisol - ?Addison's
- Specific infection serology if indicated clinically e.g., HIV
- ECG, holter monitor, echocardiogram – OI symptoms
- Sleep studies - OSA or other
- Coeliac antibodies & genetics – DQ2 & DQ8
- D-Dimer and Coags for long COVID

Other or concurrent...?

Things to treat first

- Obstructive sleep apnoea
- Multiple Sclerosis
- Iron deficiency
- Anaemia
- Thyroid disorders
- Diabetes mellitius and insipidus
- Cardiopulmonary disease
- Primary adrenal insufficiency
- Coeliac disease or food allergy
- Eating disorders
- Autoimmune disorders e.g. SLE, PMR,
    - Sjögren's syndrome

Concurrent disorders

- Orthostatic intolerance – POTS, NMH
- Gynacological issues e.g. pelvic congestion syndrome, dysmenorrhea, PMS
- Gastrointestinal issues – IBS, IBD
- Food intolerances,
- Allergies
- Oral and dental issues
- Connective tissue disorders e.g. hEDS
- Fibromyalgia
- Mental health issues
- Small fibre neuropathy

Red flags

- Severe, new onset, or worsening breathlessness or hypoxia
- Syncope
- Unexplained chest pain /cardiac
- New confusion
- Focal neurological signs or symptoms
- Multisystem inflammatory syndrome in children
- Raised CRP/ESR
- D-Dimer significantly raised/abnormal coag

What is different with long COVID?

- Clinical history of acute COVID-19
- Laboratory tests may show inflammatory marker elevation
- Pulmonary function testing with DLCO - lung abnormalities
- Neuropsychological testing documents cognitive impairment– mechanism difference micro clots/SPCT
- Chest CT - lung fibrosis or other structural changes
- Cardiac MRI - myocardial inflammation or damage

(Griffin, 2024)

Initial Management

- Listen to the patient's story
- Take time
- Involve family and support people where appropriate and if desired by the patient
- Be clear that the goals of treatment are:
  - prevention or minimisation of PEM
  - symptom relief
  - improved quality of life
  - advocacy and validation

Initial Management

- Helps to give a diagnosis
- Assess immediate needs - Centrelink or Income Protection
- Access to care - telehealth & home visits
- Book subsequent appointments – **don’t wait for issues to arise**
- Provide written notes
- Provide reassurance of support

“I don’t know all the answers, but I’m here to work with you”

Communicating and sharing knowledge

Explanation of findings:

"Looking at your tests and history, you meet the criteria for ME/CFS/long COVID"

"These issues are contributing to your symptoms"

*"Before I make a diagnosis, we need to treat *these issues*.
Then we can re-check where things are at."*

Communicating and sharing knowledge

But what if nothing has been found on tests and the physical exam is “normal”?

“We haven't found anything on your tests, but that doesn't mean nothing is wrong. It just means we can't test for it yet. Your symptoms and history tell us you meet the diagnosis for ME/CFS (or long COVID).”

Communicating and sharing knowledge

First steps for management:

“Our goal is to address these identified issues in small steps”

“What do you want to work on first?”

“Who else is part of your team? Would you like to me to include them in any communication?”

“There is nothing that works for everyone…and there is no magic cure - don't waste time or money on those who claim they can cure you. If there was a magic cure then everyone would know about it”

Communicating and sharing knowledge - PEM

Explain pacing energy with a broken battery:

"Leave some charge in your battery"

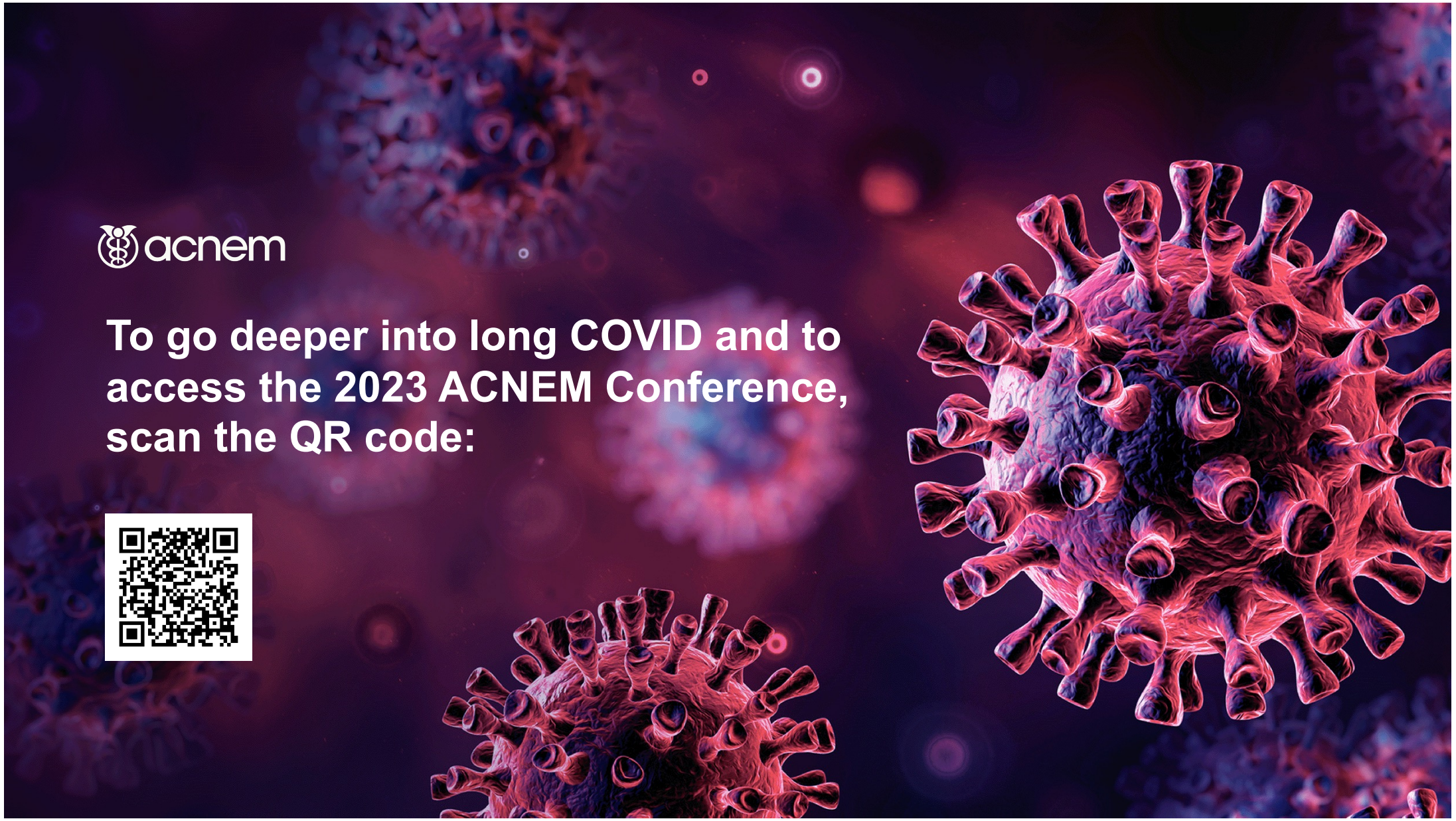
"You can run on adrenalin, but you will pay with interest later on"

"You need to only do 60-80% of what you think you can do"

Safe activity management

DO NO HARM	DON'T DO
Pacing: Stop, rest, pace [3] Pacing will not address the underlying disease but can play an important role in improving the patient's functional capacity. A tailored exercise program can be incorporated, conducted within the patient's energy capacity, with ongoing evaluation	**Graded Exercise Therapy** (inappropriately prescribed excessive exercise amount and gradations) Fixed increments of increasing exercise, pushing the patient beyond energy capacity
Refer to aware allied health professionals and/or community agencies [4] For biopsychosocial support associated with the impact of ME/CFS and/or Long COVID	**Cognitive Behaviour Therapy** (as treatment for the cause of ME/CFS)

(Decary et al, 2021; Haunhorst et al, 2024; NICE 2021)


acnem
To go deeper into long COVID and to access the 2023 ACNEM Conference, scan the QR code:

Emerge Australia can help your patients.

Emerge Australia offers a range of support through our patient support services.

We can help navigate topics that:

- Help in understanding the condition
- Explore social support options
- Help to prepare a strong DSP/NDIS application
- Support energy and activity management
- Aid in communicating healthcare requirements
- Connect people with their community
- Provide virtual community support services

Next week…

- 2 Dec 6pm AEDT

"Optimal management of common symptoms and co-morbidities"

- What are the "small steps" for sleep, pain, dysautonomia, MCAS?
- What do you already have in your toolkit?
- What is different about medication prescribing in this population?

Resources

- Symptom severity and hierarchy chart:

https://emerge.org.au/wp-content/uploads/2023/04/symptomseverityhierarchyfromthinkgp.pdf

- NASA lean test:

https://emerge.org.au/wp-content/uploads/2023/04/nasa-lean-test-instructions.pdf

- Pacing fact sheet for patients:

https://emerge.org.au/wp-content/uploads/2023/11/Pacing-factsheet.pdf

- Energy management considerations for your practice:

https://emerge.org.au/wp-content/uploads/2024/06/MECFS-friendly-healthcare-practice-rebrand.pdf

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We value your feedback