

NEL Long COVID 2023/24 Training Schedule for Health and Care Professionals

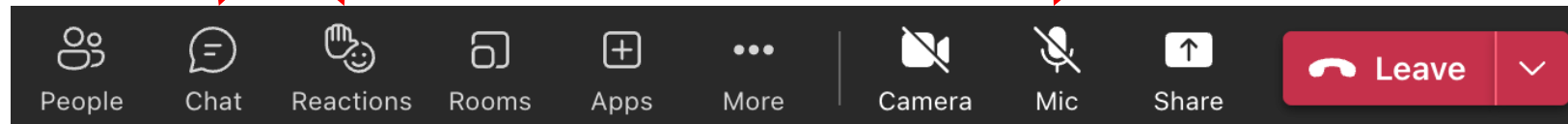
WELCOME

THE WEBINAR WILL START AT 12PM

Webinar 3: **Fatigue Management in Long COVID**

Please only use the **chat function** or
raise your hand if you would like to speak.

Please **stay muted** during the webinar
to avoid any background noise.





Fatigue Management in Long COVID

NEL Community of Practice

Joan Lim – OT, Tower Hamlets and Newham

Helena May – Physio, City and Hackney

Eleanor Dunn – SLT, City and Hackney

Session Overview

Understanding Long Covid Fatigue & The Role of Primary Care

Signposting and resources for primary care

What we do in a Rehab Service

Q&A

Understanding Long Covid Fatigue & The Role of Primary Care

Case definitions



Acute COVID-19: signs and symptoms of COVID-19 for up to 4 weeks.



Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 to 12 weeks.



Post-COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are *not explained by an alternative diagnosis*.

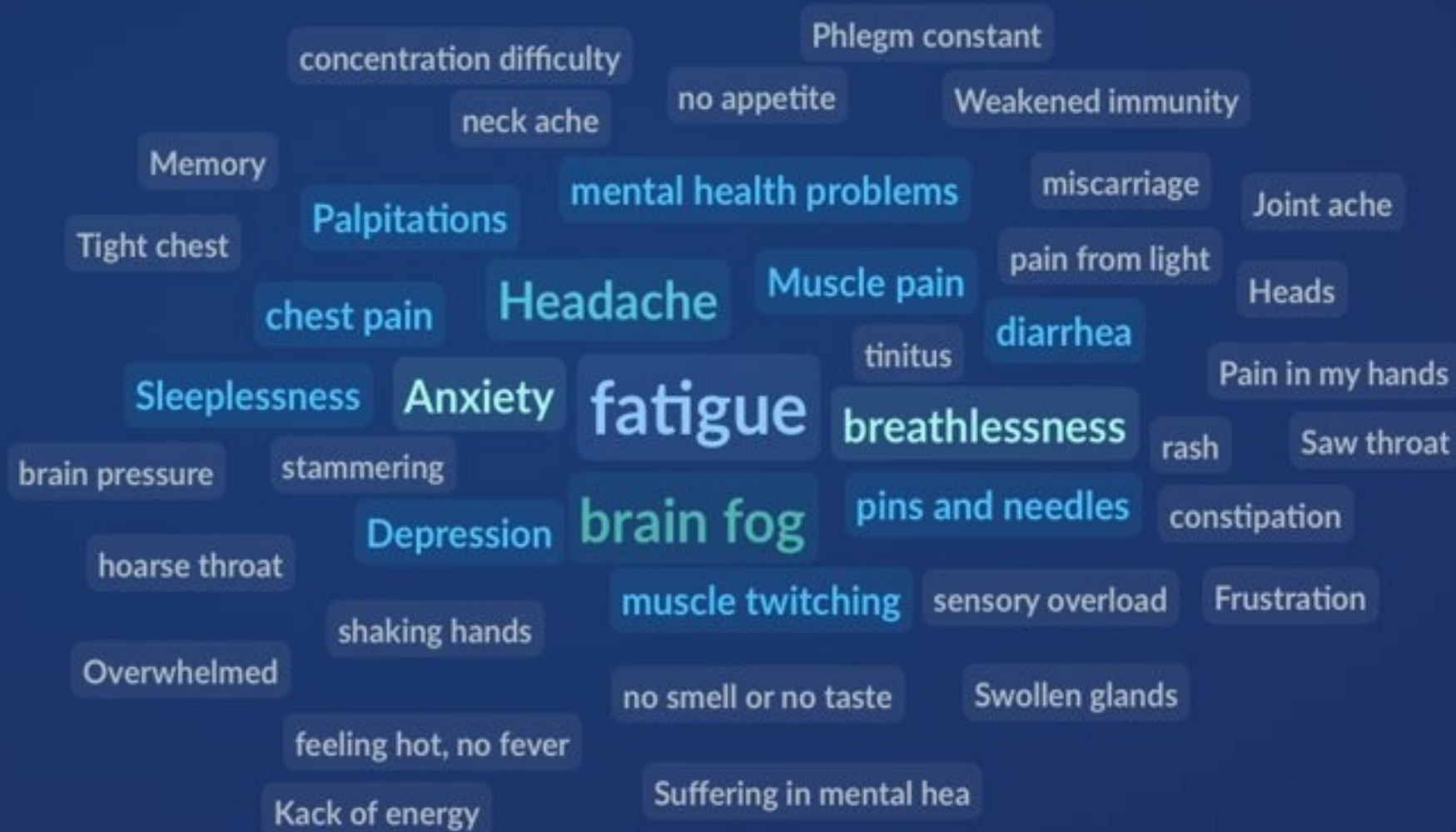
Long COVID is commonly used to describe signs and symptoms that continue or develop after acute COVID-19.

NICE National Institute for Health and Care Excellence

RCGP Royal College of General Practitioners

Healthcare Improvement Scotland | **SIGN**

What are your current symptoms?



Fatigue and Brain Fog in Long COVID

Fatigue

- Exhaustion that persists after resting, affecting physical activity and emotional, social, cognitive function
- Post-exertional malaise / symptom exacerbation (PEM / PESE) : worsening symptoms after activity
- Patients' descriptions:
 - "Moving through treacle"
 - "Spark is gone"
 - "Remote-feeling, as though the real me is sitting back far away and I can't get the messages through".

"Brain Fog"

- Cognitive symptoms that have some fluctuation
- Davis et al (2020) – 55.4-58.8% in survey of 3,762 participants reported cognitive dysfunction mainly:
 - Reduced sustained attention
 - Memory difficulties – recall and working memory
 - "Difficulty thinking" - slowed information processing and slowed executive function e.g. problem solving, decision making
 - Word finding difficulties

Working hypothesis (as in ME / CFS, post-viral fatigue and Fibromyalgia theory) is that fatigue is due to **Autonomic Dysregulation**

Fatigue, Low Mood, Stress, Anxiety

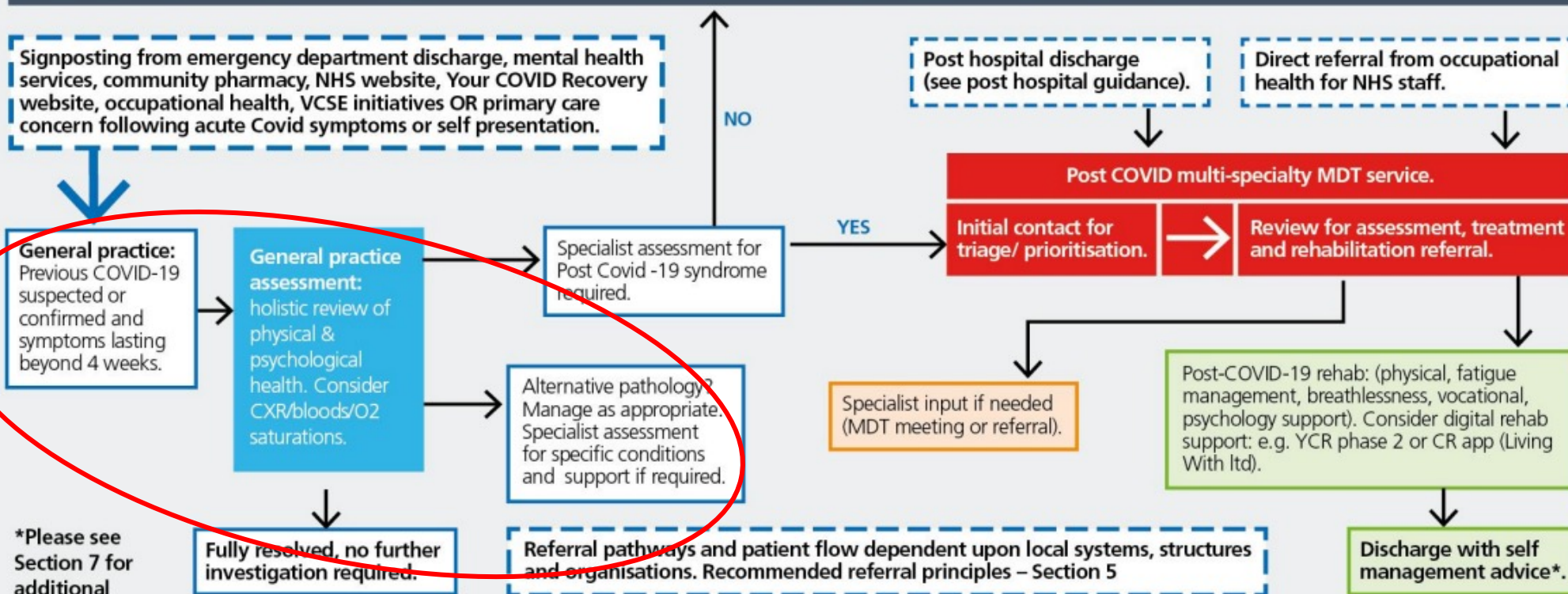
- **Autonomic Dysregulation Theory**
- **Psychological and Physical Assessment in Long COVID Teams**
 - Decision-making around best treatment at this point: the Long COVID teams treat mental health symptoms and can refer back to GP or to other teams as required.
- **JAMA Psychiatry paper:** *Is psychological distress before SARS-CoV-2 infection associated with risk of COVID-19-related symptoms lasting 4 weeks or longer?* (Wang, Quan, Chavarro et al, 2022).
 - NB: Large cohorts of predominantly female nursing staff
 - Participants with **2 or more types of distress** (probable depression, probable anxiety, worry about COVID, perceived stress, loneliness) were **at nearly 50% increased risk for Post-COVID conditions**.
 - Recommendation that *“Future work should examine the biobehavioural mechanism linking psychological distress with persistent post-infection symptoms”*

Figure 1: Primary care/community post COVID syndrome pathway for adults (Source: [National commissioning guidance for post COVID services](#))

Primary care/community post-COVID-19 syndrome pathway for adults

Code appropriately: Assessment from 4-12 weeks - Code: 'On-going symptomatic COVID-19'. Assessment after 12 weeks - Code: Post-COVID-19 Syndrome

At all stages of the pathway: Offer online self-management information and guidance (YCR Phase 1), Primary care team, wider community/peer support, social prescribing, +/- therapy, vocational rehabilitation, well-being and psychological therapies depending on the needs of the individual.



*Please see Section 7 for additional details

Support access and follow up for underserved groups. Ensure care coordination of all support/treatment

Ongoing monitoring of patients as required in primary care

Referral Pathway

- Barriers to referral process (as reported by patients) ([The-NHS-plan-for-improving-long-COVID-services_July-2022](#)):
 - Difficulty accessing a GP appointment
 - Uncertainty regarding the long COVID pathway
 - Not being listened to by healthcare professionals
 - Delays in access to diagnostics
 - Access to information and advice.
- Where Primary Care Can assist:
 - Providing education on the Long Covid Services (leaflets and handouts) and what this entails
 - To validate their symptoms, provide support

Referral Criteria for Rehabilitation Services

Inclusion

- COVID-19 symptoms (not necessarily a confirmed diagnosis) for longer than 12 weeks
- Participants have a General Practitioner in the borough(s) of the Rehab Team
- The referring medical clinician has completed all medical investigations that could attribute to the symptoms experienced. Mandatory Investigations: Full blood count eGFR Urea and electrolytes Liver function tests C-reactive protein Ferritin Creatinine Kinase
- The correct referral form is received and completed in full

Exclusion

- Under 18 yrs
- Symptoms experienced < 12 wks of acute infection
- Where the patient has not undergone a standard face to face assessment in a primary or specialist care setting
- Symptoms are acute or life-threatening
- Where a patient has symptoms where an alternative cause has not been thoroughly investigated or ruled out.

Symptoms	Medical Investigation Needed (MANDATORY)	Comments
Fatigue	1) HbA1c 2) Thyroid Function Test 3) Vitamin D Level 4) B12 Level 5) Serum Folate level 6) Bone Profile 7) Brain natriuretic peptide 8) Electrocardiogram (ECG)	“Im so tired all the time”, “Im exhausted” “I can’t get out of bed”. May also c/o Brain fog- although there is no mandatory investigation for brain- but you may consider a cog screen or a referral to the Memory clinic.
Dyspnoea (SOB)	1) Brain natriuretic peptide 2) Chest x-ray (CXR) 3) Electrocardiogram (ECG)	Upon rest and exertion. “I can’t catch my breath” “Feels like something heavy on my chest” You can hear their SOB sometimes in conversation.
Cardiac Symptoms	1) Chest x-ray (CXR) 2) Electrocardiogram (ECG)	Includes c/o chest pains and palpitations. Ahythmia or POTs
Coughing	1) Brain natriuretic peptide	

Key Messages

- Rehab service --> Medical aspects held by primary care
- Normalising fatigue in acute/sub-acute stages of a virus/Covid-19
- 0-8weeks post acute virus- support held in primary care- normalising/validating/linking to self-management resources
- If persistent fatigue (+ other symptoms) ~8 weeks, reasonable to commence Post-Covid Syndrome differential diagnosis process (i.e. ordering investigations)
- Aware the referral process is lengthy, Post Covid Syndrome = Diagnosis of elimination (important to rule out/treat other causes)
- If unsure, we welcome A&G enquiries

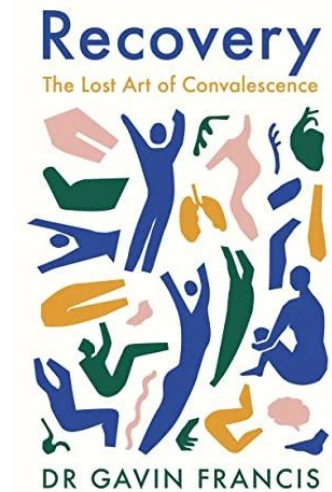
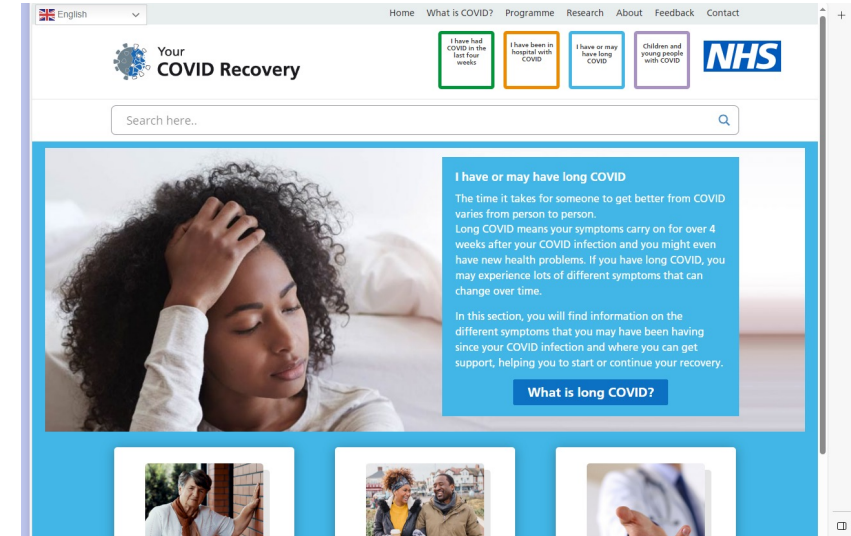
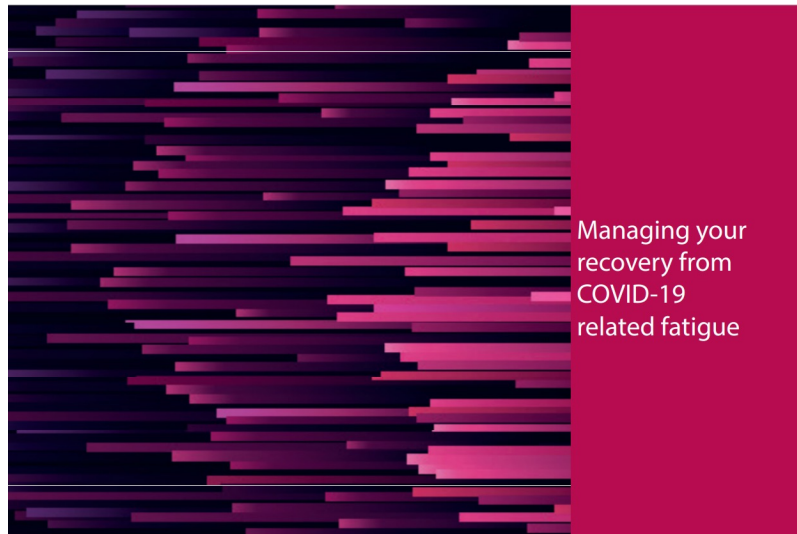
Resources for Primary care



Home > How to manage post-viral fatigue after COVID-19

How to manage post-viral fatigue after COVID-19

Practical advice for people who have recovered at home





YouTube^{GB}

Search



COVID-19

Get the latest information from the NHS about coronavirus.

[Learn more](#)

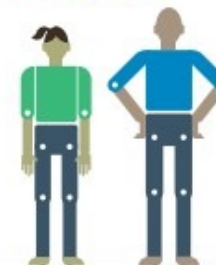


World Health
Organization

REGIONAL OFFICE FOR
Europe

Support for rehabilitation: self-management after COVID-19-related illness

second edition



Name: _____

Onset of COVID-19 symptoms (date): _____

Date this leaflet was given: _____

Name and contact details of health care
professional providing leaflet: _____

5°C. Clou

- <https://www.youtube.com/watch?v=ejqUoOjExM0>

What we do in a Rehab Service

Who are we? Rehabilitation Teams

Condition Management Therapists

Physiotherapists

- Condition Management
- Respiration
- Post-Exertional Malaise
- POTS

Occupational Therapists

- Condition Management
- Cognition
- Vocational Rehab

Speech and Language Therapist

- Condition Management
- Cognition
- Vocational Rehab

Rehab Assistants

Psychological Therapists

Clinical Psychologists

Psychotherapist

Cognitive Behavioural
Therapist

Psychological Wellbeing
Practitioner

Community and Social Support

Engagement Lead

Care Co-ordinator

Rehab Services can help people with Long COVID to:



Make sense of their symptoms



Learn strategies to manage problems such as fatigue, pain, brain fog and breathlessness



Identify and work towards values-based goals



Manage difficult thoughts and feelings



Have a setback plan

The Spoon Theory



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.



The Spoon Theory was written by Christine Miserando, which you can check out on her website www.butyoudontlooksick.com.

www.dysautonomiainternational.org

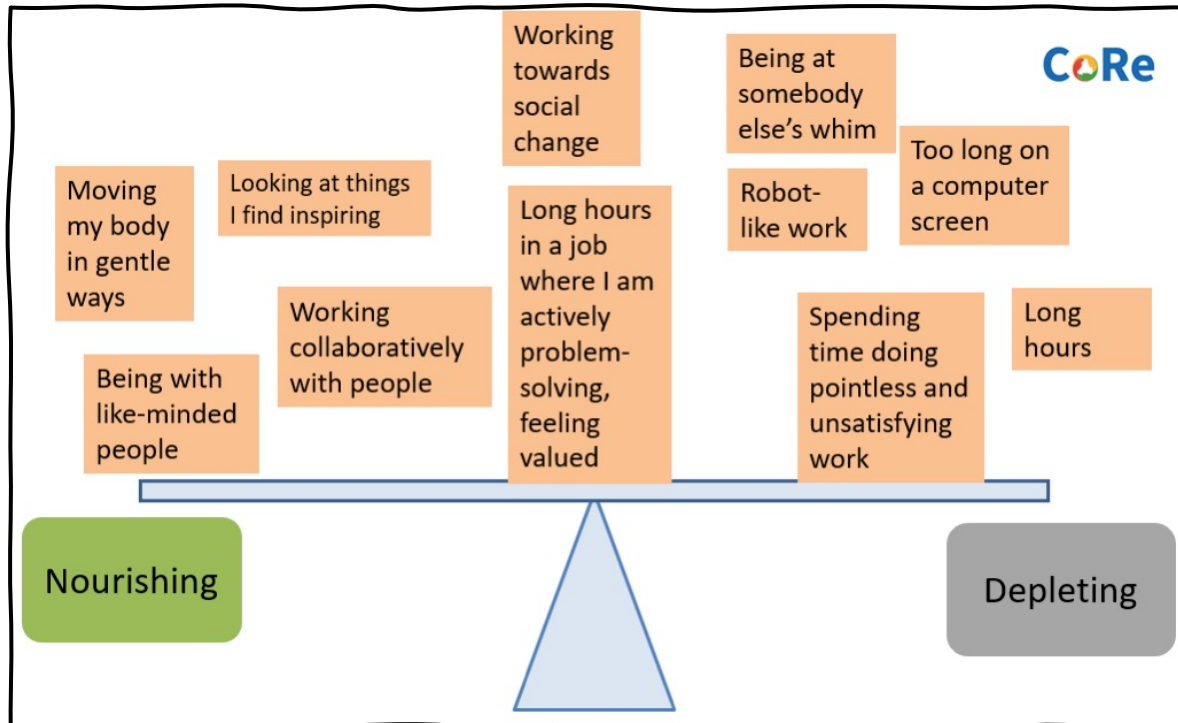
The 3 P's

Boom and Bust

Energy Conservation

What do we do?

E.g. Activity Management - Spectrum of energy-using activities, then making connections, generalising and applying to both physical and psychological situations



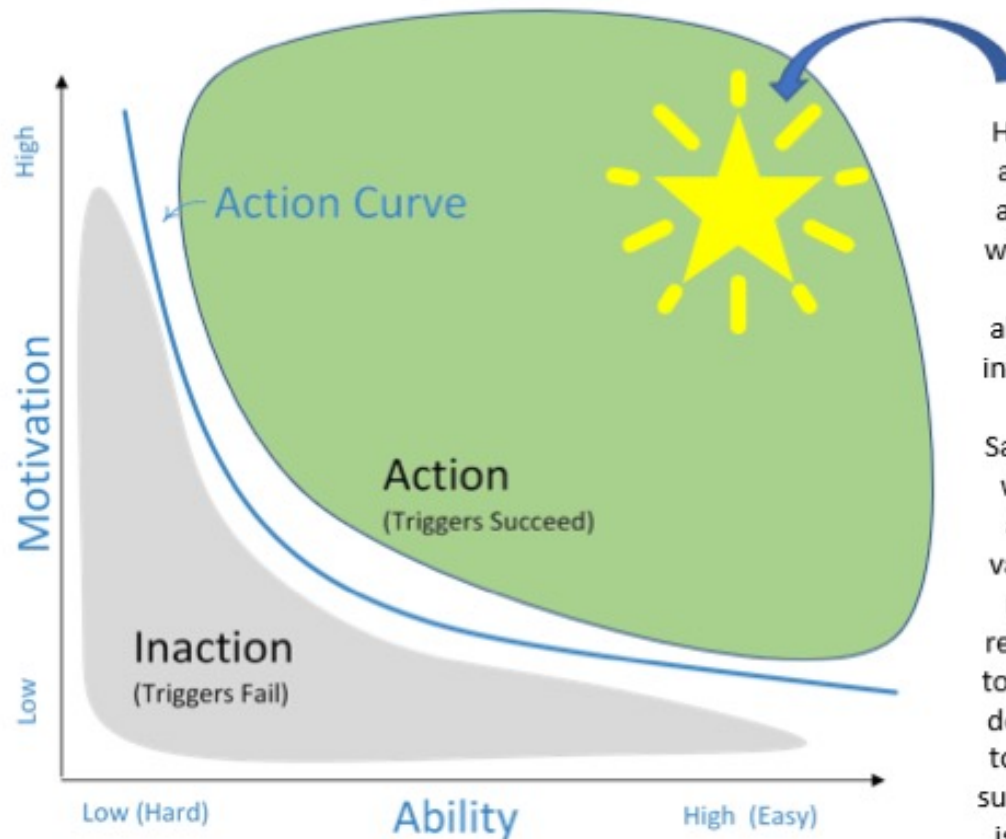
	Nourishing	Depleting
Body sensations	Presence, alertness Feeling of the senses – listening, watching – animals, wind Easy movement	Fidget Rushing feeling Tensing shoulders, spine – on guard, vulnerable Adrenaline rush – difficult to shake off, residual in the body Heaviness, slowing down
Thoughts/Feelings	Laughter Awe – connection with something beyond self Peacefulness Happy Concentrated Animated Connection, sharing interest	Quick thoughts, to do lists rushing through mind Taking things very personally, feeling preoccupied, paranoid Catastrophising Concern about Taking things personally



What do we do?

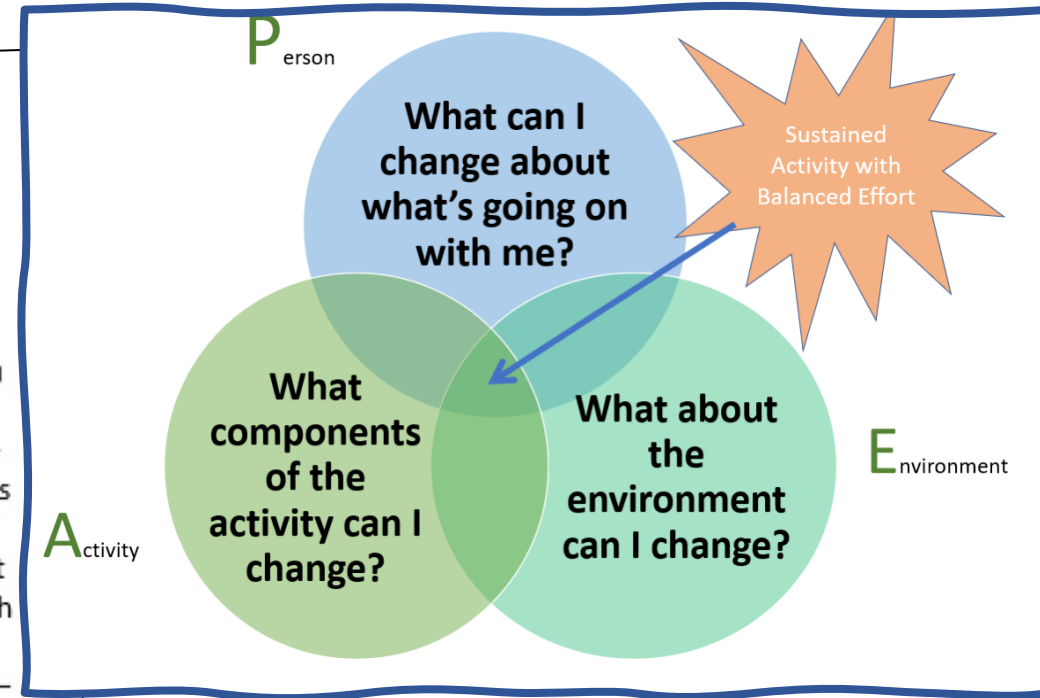
E.g. Behaviour change and modifying activities

What feels “workable”?



Here is where you are most likely to achieve success – when motivation is high and ability/ease to put into practice is high

Said another way – when something aligns with your values/what really matters and is a really small change to what you usually do, it is more likely to happen (and be sustained if the idea is to create a new habit)



Concluding comments

- Aim of LC Rehab Services is confident self-management of fatigue so that people with LC are better able to engage in ADLs, exercise, work, meaningful activity, and experience improved mood, social lives and hopefully then health too.
- Knowledge on its own isn't enough to elicit behaviour change:
 - Insight, motivation and ability are all key active ingredients which therapeutic relationship can develop.

April 2022 64% of Post Covid Services collected data from the Friends and Family Test. Of 446 participants who responded:

- 93% rated this as good or very good service
- 97% said they were treated with respect and dignity
- 95% said they were involved as much as they wanted to be in their care and treatment

[The-NHS-plan-for-improving-long-COVID-services July-2022](#)

Contact Details: Long Covid Rehab

- Newham & Tower Hamlets:
 - Longcovid.elft@nhs.net
 - 020 7909 3676
- City & Hackney:
 - **WeLCoME Service- Wellbeing in Long COVID and ME/Chronic Fatigue Syndrome (ME/CFS) Service**
A collaboration between:
 - City & Hackney COVID Rehab Service and Locomotor ME/Chronic Fatigue Syndrome (ME/CFS) Service**
 - Community & Children's Services Division
 - Homerton Healthcare NHS Foundation Trust
 - St Leonard's | Nuttall Street | London | N1 5LZ
 - Tel: 0207 683 4336
 - Email: huh-tr.welcomeservice@nhs.net

Q&A

References/Resources

- [Associations of Depression, Anxiety, Worry, Perceived Stress, and Loneliness Prior to Infection With Risk of Post–COVID-19 Conditions | Coronavirus \(COVID-19\) | JAMA Psychiatry | JAMA Network](#)
- [https://www.england.nhs.uk/wp-content/uploads/2022/07/C1607_The-NHS-plan-for-improving-long-COVID-services_July-2022.pdf](#)
- [Assessment of fatigue - Differential diagnosis of symptoms | BMJ Best Practice](#)
- [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](#)
- [C1669 Long-Covid-Toolkit Advice-and-resources-for-healthcare-professionals-in-primary-care_July-2022-1.pdf \(england.nhs.uk\)](#)
- [Assessment of fatigue - Diagnosis Approach | BMJ Best Practice](#)
- [How to manage post-viral fatigue after COVID-19 - RCOT](#)
- [https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiFje3Gw-SCAxWy87sIHaxEB2gQFnoECBQQAQ&url=https%3A%2F%2Fwww.shu.ac.uk%2F-%2Fmedia%2Fhome%2Fresearch%2Fawrc%2Fbooklet-v9-30_09_2020.pdf%3Fsc_lang%3Den%26hash%3D46725996D9F3CE332E1561E9A02205CE&usg=AOvVaw2Cy7MDA8uw98O5wkLtKkCZ&opi=89978449](#)
- [Long COVID Fatigue - Your COVID Recovery](#)