

Long COVID and Rehabilitation

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www.yourcovidrecovery.nhs.uk



NICE defines **post-COVID syndrome** (also known as **Long COVID**) as:

Signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for **more than 12 weeks** and are not explained by an alternative diagnosis

The condition usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system within the body

Many people with post-COVID syndrome can also experience generalised pain, fatigue, persisting high temperature and psychiatric problems

What is chronic fatigue?

Chronic fatigue syndrome (CFS) is a long-term illness with a wide range of symptoms – the most common symptom is extreme tiredness

- CFS is also known as ME, myalgic encephalomyelitis
- CFS/ME can affect anyone including children and is more common in women, tending to develop between mid-20s and mid-40s
- Recognised before Long COVID

Treatment for chronic fatigue

- A structured exercise programme graded exercise therapy
 new guidelines refer to exercise envelopes
- Medication for pain, nausea, sleep etc.
- Cognitive behavioural therapy (CBT)
- Most people with CFS will improve over time, especially with treatment, although some people do not make a full recovery
- It's also likely there will be periods when symptoms get better or worse
- Children and young people with CFS/ME are more likely to recover fully

The Energy Puzzle

Social

Emotional

Mental

10 tips for better sleep

The human battery: supply and demand

The post viral battery

It's become smaller than usual

It flattens quickly /deconditioned

It takes ages to recharge

Every activity requires energy:

Ways to improve the battery

- Avoid the boom and bust
- Pace Plan Prioritise
- Rest/Keep charging it up
- Chunking/Set the limits
- Save 30% in the bottom
- Good sleep
- Diet and hydration
- Gentle exercise/stretches
 Have fun

Avoid the boom and bust

Finding a baseline:

- Map out energy (Diary)
- Start at a lower level than predicted 50%
- Experiment Tweak
- Fatigue increases but resolves quickly
- Give the body time to adjust before increasing
- Are you doing too much on some days, followed by periods of inactivity where you catch up?
 e.g. Boom-bust pattern

The Three P's

What do you currently do that works?

Pacing

- Take regular breaks every 2 PACING
- Set an alarm
- Break up activity into manageable chunks
- Categorise and mix-up activities during the day

08:00 Get Dressed physical

08:45 Breakfast nutritional

08:30 Rest

U9:UU Kest

PRIORITISING

09:20 Call friend / family member social

PLANNING

09:40 Rest

10:00 Online banking *mental*

Exercise

Only once sustainable baseline established

Start low go slow

Increase by one small task/activity or lengthen an existing task/activity

Go slowly and gently to avoid setbacks

Extend by 10% (severe cases)

Normal effects of increase vs overdoing it

Manage emotions (frustration/guilt)

Emotions + Thoughts

Many patients have reported changes coping after the COVID 19

- Feeling more anxious
- Poor memory
- Poor levels of concentrations
- Fear about returning to their pre-COVID self
- Fear of getting it again

This is normal following a period of illness

COVID rehab pilot – Outcomes

Incremental shuttle walking test

• EQ 5D

- Gad 7 PHQ 9
- Fatigue severity scale
- Borg breathlessness scale
- Satisfaction questionnaire

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Cor	nments		
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feel able to ontinue with the xercise rogramme after e course?	x		Did you fir	nd the educa	ation sessio	ns helpful?			
eel more active my day to day	х				Very	Quite	Not yery	Not	Comments
eel that my ality of life has	х		What is Co	ovid?	Helpful	Helpful	helpful	Helpful	
proved. e programme et my	x		Breathlessness Management		X				
ould			Managing Nutrition	Fatigue	X	X			
ecommend the programme to others recovering	Х	e L	Speech and anguage	d	~	X			
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	exercise	s (1hr)	X						
	education	gin of the on s (1hr)	x						
1		of MS							

COVID Rehabilitation Pilot Programme – Educational Talks

COVID	Dr Abi Moore
ITU	Dr Chris Westall
Breathlessness	Jenny Gates (Physio)
Fatigue	Dr Kim Van Mouwerik
Eating Well	Jenny Murphy (Dietitian)
Psychological awareness and resilience 1	Dr Maria Smaga
Swallow, Voice etc.	Hilary Armstrong (SLT)
Psychological awareness and resilience 2	Dr Maria Smaga
Energy Conservation	Kelly-Ann Keeling (Physio)
Psychological awareness and resilience 3	Dr Maria Smaga
Cohort Q&A	Ruth Barlow (Physio)
Family and Friends	Sue Webb (Physio)

Results – Shuttle Walk

Outcomes:

- No hospital admissions during the 6 week course
- Shuttle mean improvement 92m, significant change 45m
- Borg improved resting and exercise by 1.7 and 1.2 respectively significant change 1
- Anxiety improved
- Depression no change
- Fatigue improvement 1.4 significant 0.45 0.88
- Good satisfaction
- EQ 5D (quality of life) to be analysied

Patient email – post rehab

I just wanted to express my appreciation to you and your colleagues for the invaluable help that you've all been to me over the last six weeks or so of the rehab course.

After completing the follow up walking assessment in Halstead on Wednesday, I was pleased to learn that **my stamina**, **breathlessness and fatigue level had improved a lot** since the same tests were undergone before the course began.

I can only put this down to the course, not just the exercise sessions which must have helped, but especially the educational sessions on issues such as managing breathlessness and understanding fatigue.

I was very aware while I was doing the walking assessment this week that I was able to regulate my breathing so much better than I remember doing during the first assessment in October, and that's only due to the impact of doing the course.

Any questions?