Long COVID rehab program shows 'impressive results'

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A rehabilitation program that helps people with long COVID reduce their symptoms and increase activity levels has shown "impressive" results, say scientists.

It is based on a gradual or paced increase in a patient's physical activity.

Before the start of the program, the people taking part in the program were reporting on average three "crashes" a week where they were left physically, emotionally or cognitively exhausted after mild physical or mental exertion. Six weeks later, at the end of the program, that was reduced to an average of one crash a week.

The patients also experienced a "moderate improvement" in their ability to be active and better quality of life.

The pacing program was run by the long COVID service at Leeds Community Healthcare NHS Trust and evaluated by clinicians and scientists at the University of Leeds and Leeds Beckett University. The findings are reported today in the *Journal of Medical Virology*.

Writing in the paper, the research team say the program, which involves a supervised increase in physical activity, has the potential to be an effective treatment option.

Dr. Manoj Sivan, Associate Clinical Professor in the School of Medicine at the University of Leeds, Consultant in Rehabilitation Medicine at Leeds Teaching Hospitals NHS Trust and research and service evaluation lead for the long COVID service at Leeds Community Healthcare Trust, supervised the research project.

He said, "Long COVID affects around two million people in the UK and it has an impact on their quality of life and in some cases, their ability to work. It is distressing and disabling.

"Post-exertional malaise or post-exertional symptom exacerbation or simply 'crashes,' as described by patients, is a defining and important symptom of long COVID.

"When patients get a crash, they experience feelings of complete exhaustion and wipe out and are unable to resume activities for hours or sometimes days.

"The findings of this research are exciting because this is the first time that crashing episodes have been used as a marker for the condition and a structured pacing program has now been shown to substantially reduce symptoms and improve quality of life."

Paced return to physical activity

Thirty-one people with long COVID took part in the six-week study in Leeds. On average, they had been experiencing long COVID for around 17 months before entering this program. They were suffering from a range of symptoms along with fatigue, including brain fog, breathlessness, headache and palpitations.

The patients followed a gradual return to physical activity program called the World Health Organization (WHO) CR-10 Borg pacing protocol, which takes them through five levels of activity. They followed the program at home.

The first phase is a preparation for return to activity and involves breathing exercises and gentle stretching. The fifth phase involves activities the patients were doing before they were ill such as regular exercise or sports.

During the program, the patients had weekly phone calls from their long-COVID clinician to check on their progress. They were told to stay at each level for at least seven days and not to overexert themselves, so their condition remained stable.

The patients completed a questionnaire to assess their exertion levels and

crashes each week before a decision was made whether to progress to the next level of the pacing protocol.

This protocol was developed for the World Health Organization by Dr. Sivan and his team. Dr. Sivan is the WHO advisor for long COVID rehabilitation policy in Europe.

Over the six weeks, not only was there a reduction of crashing episodes, but there were also improvements in activity level and quality of life. In terms of easing long COVID symptoms, the biggest benefit was seen in terms of reducing fatigue, breathlessness and headaches.

Legacy of long COVID

According to data from the Office of National Statistics, almost two million people in the UK have long COVID, with symptoms that have lasted for more than 4 weeks. The crash or exhaustion that people feel after exerting themselves can start 12 to 48 hours after activity and can last for days and in rare cases, even weeks.

But the researchers point out that there is still a lack of awareness among clinicians supporting long COVID patients that a paced or gradual return to physical activity could aid recovery.

Writing in the journal, they noted: "This study adds to the current understanding by demonstrating the potential of a structured pacing protocol to gradually improve activity levels... Yet, current advice on safely returning to physical activity without worsening their symptoms is unclear, with patients reporting receiving differing advice from health care professionals."

Dr. Sivan's research team has been at the forefront of new initiatives to treat long COVID. They developed the first scale to standardize the

measurement of long COVID symptoms, which has now been developed into a mobile phone app, used by patients, which is linked to a web platform used by the clinicians treating them. NHS England recommends the use of the digital system in long COVID NHS services.

The researchers are also conducting a major pan-UK platform study called LOCOMOTION that is developing a gold standard of care for the condition.

More information: Megan Parker et al, Effect of using a structured pacing protocol on post-exertional symptom exacerbation and health status in a longitudinal cohort with the post-COVID-19 syndrome, *Journal of Medical Virology* (2022). DOI: 10.1002/jmv.28373

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