

Post-COVID-19 syndrome (long-COVID)

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What is post COVID syndrome?



NICE Definitions of COVID related illness

- **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).

Beware of poor quality research with unclear
denominators

Who gets Long COVID?

- Five to ten percent of patients at 3 months
 - Wide range of estimates
 - Little long term follow up and selected samples
- Older patients
- Females
- Pre-morbid vulnerability

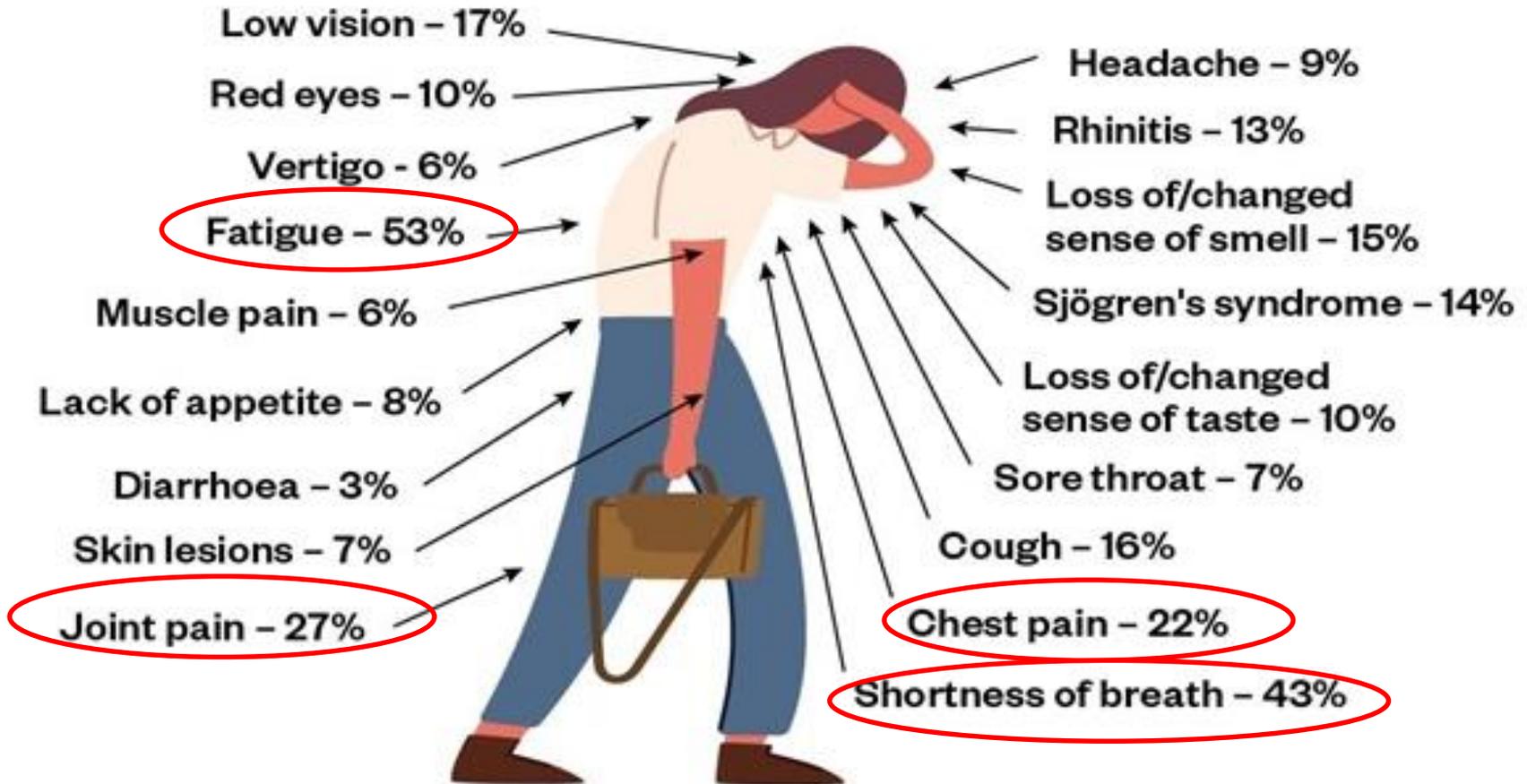
The post-COVID clinic in Oxford

- Sees patients post-hospitalisation and also GP referrals
- Multidisciplinary: hospital clinic and community rehabilitation
 - Respiratory
 - Rehabilitation
 - Psychiatry
 - Psychology
 - Physiotherapy
 - Plus virtual MDT
- Based on NICE guidelines (and short-term funding)

Case study from the post-COVID clinic.

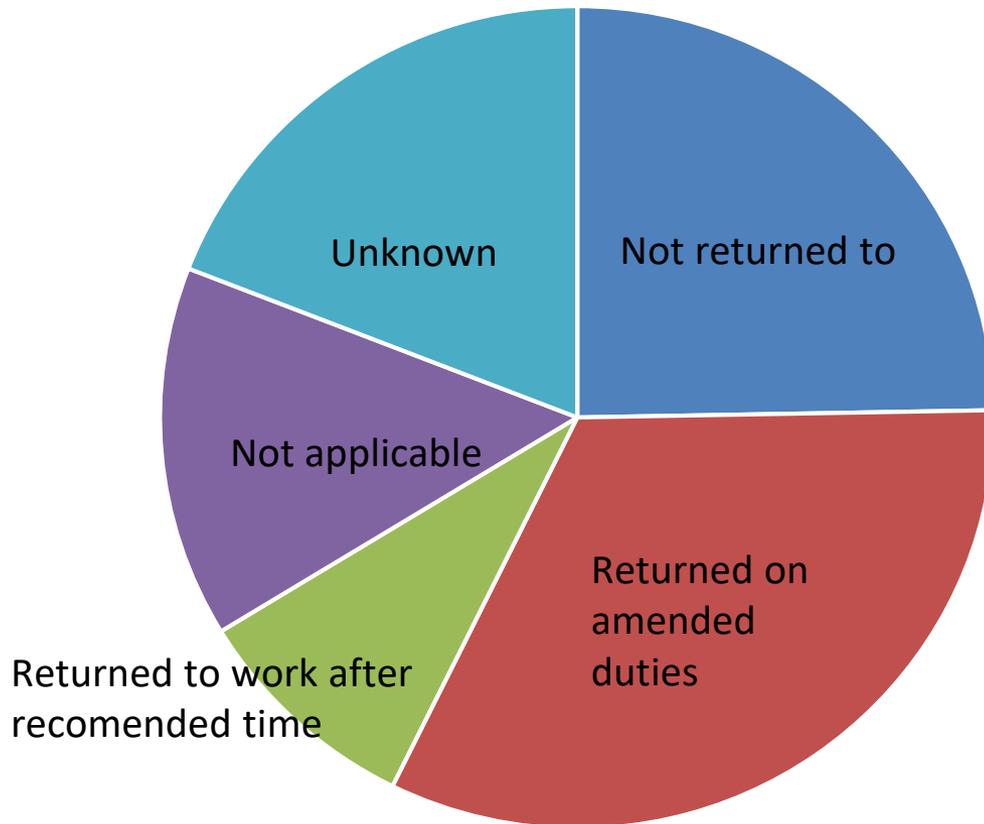
- 35 year old woman referred by her GP
- Teacher with 3 small children
- 'COVID like' illness - not hospitalized - six months ago
- Now disabling fatigue made worse by exertion, aches shortness of breath and heaviness in chest. Anxious.
- Unable to work

Symptoms of post-COVID Syndrome



Source: JAMA 2020;324(6):603-605.

Employment status of 100 patients seen in Post COVID clinics at 6 months



From the data available, 25% of patients had not returned to work due to extent of symptoms

What causes post COVID syndrome?



We must not assume that post COVID syndrome is a single condition with a single cause

Biological Factors

- Damage to lung, other organs and immune abnormalities
- (Reversible) dysfunction e.g. autonomic nervous system
- Effects of coping behaviour e.g. resting, abnormal breathing

Multi-symptom illness does not necessarily mean
multi-system pathology

Psychological Factors

- Seeing bodily sensations as alarming and focussing on them
- Becoming anxious and then experiencing more symptoms (significant anxiety in a high proportion of patients)
- Coping including avoidance and seeking medical care

Social factors - The media

“In some cases, long COVID could mean lifelong COVID. The effects can be horrible. Among them are lung damage, heart damage and brain damage that can cause memory loss and brain fog, kidney damage, severe headaches, muscle and joint pain, loss of taste and smell, anxiety, depression and, above all, fatigue. We should all fear the lasting consequences of this pandemic”.

George Monbiot, The Guardian, January 2021

Social factors – Support groups



COVID-19
Survivors Group UK

COVID-19's impact is felt by us all and we are only just beginning to understand some of the long term implications it can have on the physical and mental wellbeing of survivors.

At Self Help UK we know that talking to others who have had similar experiences is essential for growth and recovery. COVID-19 Survivors Group UK will be molded by its members, through your voices and opinions.

Join our Facebook group! COVID-19 Survivors Group UK
www.facebook.com/groups/COVID19SurvivorsGroup/

What to expect

- Up to Date Information & Resources
- Open Forums
- Survivor Experts
- Health Professionals & Speakers
- Webinars & Training

For further information

- ☎ 0115 9111662
- ✉ outreach@selfhelp.org.uk
- 🌐 selfhelp.org.uk/COVID-19_Survivors_Group_UK



self help uk

Doctors & Long - COVID Support Group

Doctors, do you have or feel you might have long-Covid?

If so, please feel free to attend a group run by Doctors in Distress. The group will be run on therapeutic lines and provide a confidential space for you to share your experience, but importantly gain and give support to others in a similar position.

The group will be facilitated by Dr Sae Warren and Dr Clare Gerada via Zoom.

The group will run for 75 minutes, 11am - 12.15pm with a 10-minute break after the first 40 minutes, every Wednesday, for 9 weeks on:

14th, 21st October
4th, 11th, 18th, 25th, November
2nd, 9th, 16th December



Registration for Long -COVID Group



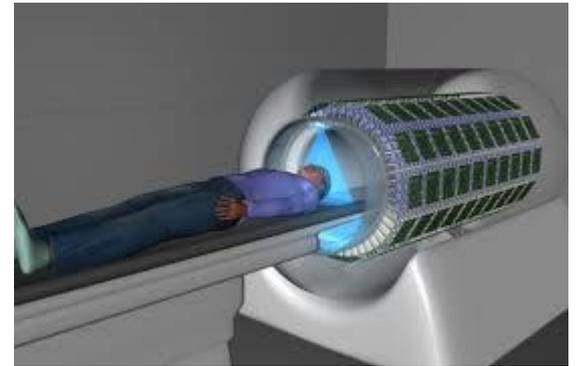
NEW Long Covid Support Group for North West Leicestershire

SUPPORT

Social factors - Doctors

These patients are just so frustrated,” he says. “Their physicians don’t believe them and so they get psych referrals. Just to be able to tell these people they have a real disease and here’s what’s causing it — that would be really meaningful.”

An immunologist (reported in Nature)



Summary of possible causes of Post-COVID syndrome

Biological

- Organ pathology and immunology
- Physiological changes such as dysautonomia

Psychological and behavioural

- Fear, focussing on symptoms anxiety and depression
- Coping behaviour

Social

- Misinformation/ online and press and iatrogenesis
- Social, interpersonal and employment issues

How can we treat post COVID syndrome?



We need to balance 'keeping an open mind' with a pragmatic approach to management

Basic Management

- Patients need to feel listened to and believed
- Physicians must manage uncertainty
- Identify and treat what is treatable (medical and psychiatric)
- Give a positive message
- Rehabilitation

There are similarities with other illnesses such as
Chronic Fatigue Syndrome (CFS/ME)

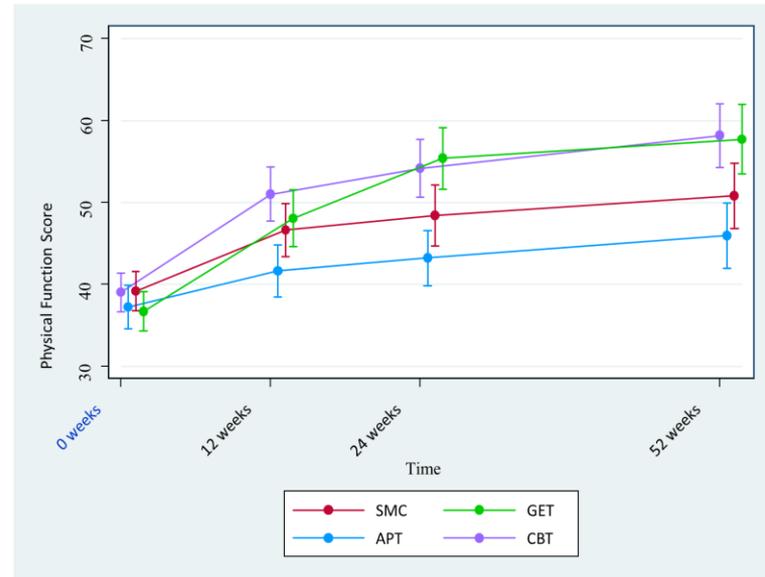
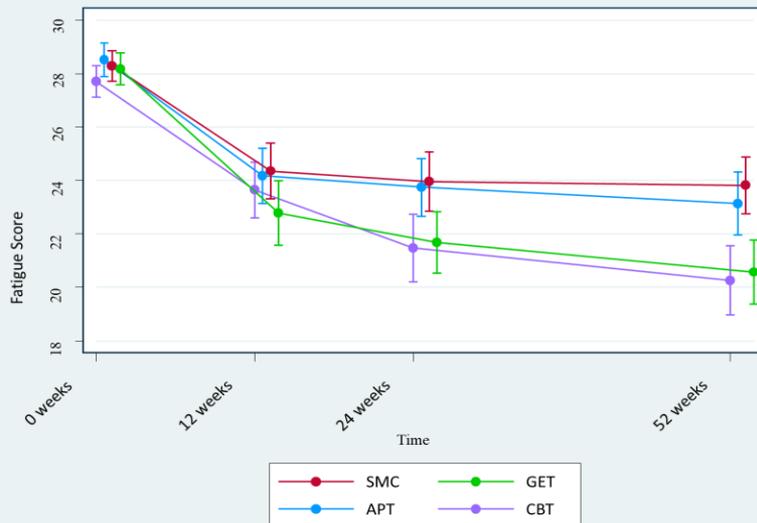
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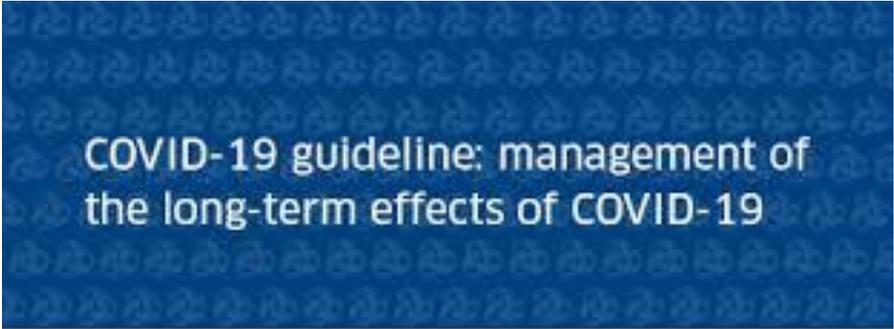
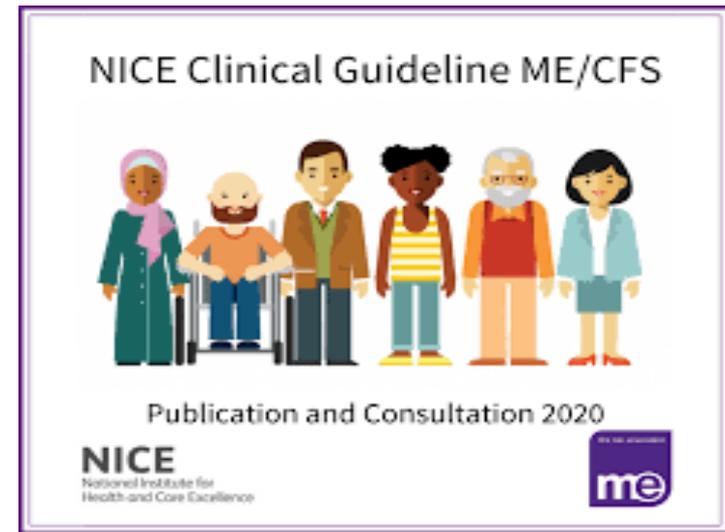
Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial

Prof PD White, MD, KA Goldsmith, MPH, AL Johnson, PhD, L Potts, MSc, R Walwyn, MSc, JC DeCesare, BSc, HL Baber, BSc, M Burgess, PhD, LV Clark, PhD, DL Cox, PhD, J Bavinton, BSc, BJ Angus, MD, G Murphy, MSc, M Murphy, FRCP, H O'Dowd, PhD, D Wilks, FRCP[Ed], Prof P McCrone, PhD, Prof T Chalder, PhD, Prof M Sharpe, MD, on behalf of the PACE trial management group†



At present the best treatment is psychologically informed rehabilitation

Challenges in providing rehabilitation



What is the outcome of post COVID syndrome?



Outcome of Long-COVID

- Most improve - but it may be slow
- Explanation and rehabilitation seem to be helpful
- We don't have much data – but the rule of thirds seems likely
- Reasonable guess is one percent will have long term disability – but will depend in part on care received.

Case study from the BMJ

- Middle aged Professor of Medicine - Paul Garner
- ‘COVID like’ illness - not hospitalized
- Disabling fatigue made worse by exertion, aches shortness of breath and heaviness in chest. Anxious and depressed. “ME”
- Unable to work
- Recovered with rehabilitation



Summary

- Beware of poor quality research with unclear denominators
- We must not assume that post COVID syndrome is a single condition with a single cause
- Multi-symptom illness does not necessarily mean multi-system pathology
- We need to balance 'keeping an open mind' with a pragmatic approach to management
- There are similarities with other illnesses such as Chronic Fatigue Syndrome (CFS/ME)
- At present the best treatment is psychologically informed rehabilitation
- There is likely to be some long-term disability

References

- NICE COVID-19 rapid guideline: managing the long-term effects of COVID-19; 18th Dec 2020
- Sykes, DL et al (2021) Post-COVID-19 symptom burden, Lung
- Garner, P (2020/21) Essays on Long-COVID, BMJ

Thank you

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