

Long Covid

Health & Safety

Polina Sparks, Long Covid Support — Eployment Group

Longcovid.org



- Longcovid.org founded in May 2020, in the first wave as a peer support and advocacy group
- <u>https://www.facebook.com/groups/longcovid</u> has 38.8K members including international
- Long Covid Europe (longcovideurope.org)
- Long Covid Physio <u>longcovid.physio</u>
- Long Covid Kids
- Long Covid Wales
- Long Covid Scotland
- Covid-19 research involvement group

Longcovid.physio



- <u>Longcovid.physio</u> founded November 2020 as a peer support and advocacy group by Physical Therapists (physiotherapist) and support workers with Long Covid in the UK and the US
- Provides resources on Long Covid and Rehabilitation, including on:
- Exercise, Fatigue and Managing Daily Activities
- Post Exertional Malaise
- Dysautonomia and POTS (Postural Orthostatic Tachycardia Syndrome)
- Heart Rate Monitoring
- Breathing Pattern Disorders
- Brain Fog

About Long Covid



What is **Long Covid**? (post-Covid condition*)

• Symptoms that persist beyond 4 weeks:

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others ** which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. A separate definition may be applicable for children.

- * WHO Delphi consensus definition, 6 October 2021
- **Table 3 and Annex 2 of the document which include chest pain, muscle and joint pain, memory problems, sleep disorders, post-exertional malaise, tachycardia, depression, anxiety, blurred vision, tinnitus, hearing problems, gastrointestinal issues, menstrual problems etc.

How long is long?

- Symptoms that persist beyond 4 weeks: breathlessness, chest pain, joint pain, tachycardia/ POTS, fatigue, headaches, brain fog, among others
- 1in 5 people diagnosed with Covid-19 have symptoms for 5 weeks+, 1 in 10 for 12 weeks (ONS). Prevalent in **over 35s**, **women** (surveys, incluging our, show that more than 80% are women, the largest age group is 45-54, but people in their 30s and 50s are also among the most frequently affected)
- From Long Covid Support survey (October 2021) more than one in three people have had Covid for 18 months+, one in four for 12-18 months and one in four for 9-12 months.
 More than 50% have been impacted for more than a year
- The Equality Act 2010 defines disability as a physical or mental impairment that has a substantial and 'long-term negative effect on ability to do normal daily activities. "Long-term" means 12 months or more. The government's own definition gives an example of "a breathing condition that develops as a result of a lung infection" this describes one of Long Covid's prominent symptoms. So whether or not Long Covid is specifically classed as a disability under the Equality Act, it falls under this definition and should be protected as such.
- Testing was not available to those in the first wave in early 2020.
- Positive test is **not required** for clinical diagnosis of Long Covid
- NICE guidelines now recommend referral to Long Covid clinics **after 4 weeks** of acute Covid (NHS England guidance has been 12 weeks)
- Long Covid clinics are not yet universally accessible. Diagnosis, treatment and rehabilitation are lagging, and waiting lists are long

"But you look well"



- Lack of testing in 2020 and diagnosis into 2021
- Prespectum's Coverscan study (incl. deep MRI scan) found:
- **70% one organ** impairment **29% multiple organ** impairments
- Heart, lung, liver, kidney, pancreas
- 42% 10 symptoms + **60%** severe past 4 weeks
- Little difference between hospitalised and non-hospitalised LC patients

"You look well"



Mental Health

- In a recent study published in Lancet in a cohort of 236,379 people after 6 months of being diagnosed with Covid-19 33.6% had an estimated incidence of psychiatric or neurological diagnosis (46.42% for those admitted to ICU) These included ischaemic strokes, haemorrages, parkinsonism, dementia, anxiety disorders 17.39% (ICU: 19.15%), psychotic incidents 1.4% (ICU 2.77%)
- PTSD is common among Covid-19 survivors as well as carers and NHS staff

Mental Health Chicken and Egg



- People with Long Covid, both hospitalised and nonhospitalised are likely to suffer from stress (potential PTSD) and anxiety.
- There can be physiological causes of **brain fog** and **fatigue** including thyroid dysfunction, micro blood-clots in the brain, dips in blood oxygen etc.
- Learning curve. When symptoms are unexplained and physiological causes unknown, it can be tempting to look for mental health reasons
- Long Covid patients struggle with disbelief and being told their symptoms are "anxiety" BUT
- Negative test results are NOT an "All Clear"

FATIGUE NOT "A bit tired"

The spoons theory

- Those who "push through" relapse harder and longer. Activity load is best evenly spread.
- Can be linked with POTS, dysfunctional breathing
- Those in **physical jobs** are anxious about returning
- Return on part days, building up
- Break tasks into manageable chunks

BRAIN FOG NOT "A bit forgetful"

- Cognitive impairment
- Executive dysfunction
- Difficulty ordering information
- Difficulty organising time
- Adjust tasks and make expectations clear
- Cognitive assessment is good practice (free resource https://www.braintreetraining.co.uk/freestuff.php)

What is needed?

- Referral to Occupational Health/ Occupational Therapy. (in our survey happened to only 50% of cases, but made a major difference). Employer following OH assessment and recommendations Referrals to physiotherapy
- **Covid safe environment** Social distancing, one way system in offices with desks, fresh air circulation (ventilation), masks wherever practical. Accessible toilets, accessible work stations (stairs? lifts? trip hazards?). Good lighting, screen filters, noise reducing head phones, recording and voice transcription software. Adjustable seating. Plug in mouse, keyboard..Paying for eye, hearing tests. **Rest breaks.**
- Phased return over at least four weeks, ideally longer. DO NOT ASSUME LINEAR RECOVERY
- Late starts/ adjustment in shifts. Flexible working
- **Allow homeworking** this is a major factor in enabling colleagues with Long Covid to stay in work!
- Phased return: starting on $\frac{1}{2}$ hours, building to $\frac{3}{4}$ etc over weeks. **DO NOT ASSUME LINEAR RECOVERY**
- Adjust tasks to capability. Can stress be avoided?
- Communication (employers to be guided by the employee). <u>Proactive union representation!</u>
 Don't let people with cognitive problems go into management meetings alone, unrepresented All comunication with managers and HR must be in writing. Insist on notes, recording.
- Mental health support. Trained **Mental Health First Aiders** to provide confidential support
- Don't focus on "at managers discretion", focus on balancing the needs of employer and employee

Look to **Society for Occupational Medicine** for guidance for employers

Positive arguments for employers

- For some employees and employers, homeworking has been positive
- Employees with anxiety, ADHD, autism may have benefitted from homeworking. Allow it to continue
- Reduced commute can increase productivity
- Increased flexibility
- Family-friendly practices
- Consider this when planning to return to offices

Avoid extra stress!



Images by Dormouse