

LIVING WITH LONG COVID

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**Supporting
Healthcare
Heroes UK**

KEY ISSUES

Background

What is Long Covid and how does it present

Difficulties in accessing appropriate medical care

Lack of support when returning to work

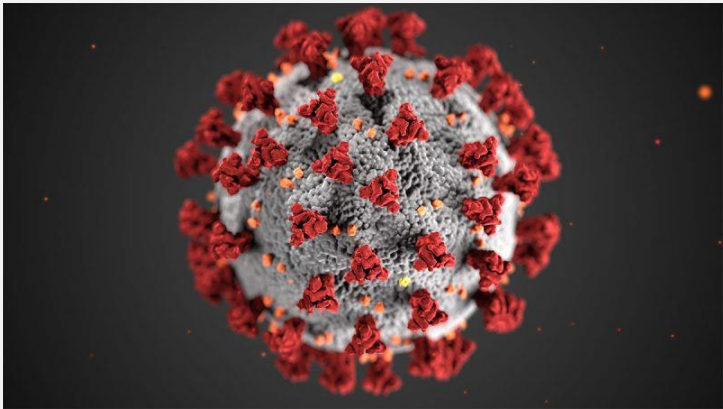
Non-evidence-based infection prevention and control guidelines

The need for *Safe Air* in healthcare settings

We don't want you or other HCP to get LC

BACKGROUND

WHO ARE WE
AS CYP NURSES



PRESENT DAY FOR US



Early (ill-health) retirement



Working reduced hours

LOSS THROUGH LC

Loss of career

Career trajectory
changed

Work
opportunities
change

Impactful
disabilities

Impact on
relationships,
family, friendships

Socialisation

IT'S A SPECTRUM

Worst
day

- Life
- Year
- Season
- Month
- Week
- Day
- Hour

Best day

DEFINITION

Long COVID (LC) is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

[One_pager_Long_COVID_Definition.pdf \(nationalacademies.org\)](#) (U.S. National Academies of Science, Engineering and Medicine 2024)

pins-and depression clotting-disorders needles
constipation rash fever diabetes abdominal-pain
cough body-pain deafness malaise joint-swelling
ptsd heart-palpitations headaches
lumps brain-fog muscle-aches post-exertion
pots chest-pain difficulty-concentrating anxiety
joint-pain breathlessness sleep-disturbances
dizziness cognitive-dysfunction
mood-changes fatigue confusion rigors menstrual
digestive-issues temperature-dysregulation
stress-difficulties diarrhoea changes
memory-problems changed-mobility

SYMPTOMS

CURRENT EVIDENCE I

Prevalence:

- In March 2023 1.9 million people in the UK were living with Long Covid (ONS 2023).
- Data in March 2024 indicates this number has increased significantly with 2 million people in England and Scotland found to be living with Long Covid (ONS 2024).

CURRENT EVIDENCE 2

Risk factors

- **Higher risk** is associated with being **female (especially aged 35–50)**, having **pre-existing conditions** (e.g. asthma, diabetes, mental health issues), experiencing **severe or multi-symptom acute illness**, and living in **socioeconomically deprived areas**.
- **Unvaccinated individuals** and those with **repeated COVID-19 infections** face increased risk, while vaccination and early antiviral treatment appear protective.
- **Health inequalities** contribute to underdiagnosis in ethnic minority and migrant populations, compounding their vulnerability.

(Al-Aly et al. 2024; Greenhalgh et al. 2024)

CURRENT EVIDENCE 3

ME/CFS like symptoms

- Around 50% of people with Long Covid meet the criteria for ME/CFS (Davis et al. 2023).

Exercise intolerance

- Many people with Long Covid are “exercise intolerant” (Palau et al. 2024).
- This needs considering when planning rehab programmes.

)

CURRENT EVIDENCE 4


Increased risk of:

- Pulmonary embolism
- Stroke
- Myocardial infarction
- Acute kidney injury
- Hepatobiliary injury
- Guillain-Barré syndrome
- Sepsis

(Greenhalgh et al. 2024)

Increased risk of:

- Diabetes (Wang et al. 2023; Al-Aly & Cao 2024).
- Pneumonia (Duong et al. 2025).
- Postural Orthostatic Tachycardia Syndrome (POTS) (Lee et al. 2023; Dulal et al. 2025).
- Mast Cell Activation Syndrome (Affrin et al. 2020; Arun et al. 2022; Weinstock et al. 2021).



DIFFICULTIES
ACCESSING
CARE -
EVIDENCE

- Turk et al (2024) qualitative study, accessing care from perspective of patients and healthcare professionals, sub study of STIMULATE-ICP-DELPHI, using Delphi technique.
- Participants - 24 patients, 8 HCP
- Data collection - interviews
- Three themes focused on facilitators and barriers
 - Patient effort to seek care
 - Interactions between patient-HCP
 - Service resources and structural constraints
- Discussion – considerable effort needed to push for right care, treatments, referrals. Limited knowledge and understanding in the professions.

doi: [10.1111/hex.14008](https://doi.org/10.1111/hex.14008)



DIFFICULTIES
ACCESSING
CARE -
LIVED
EXPERIENCE

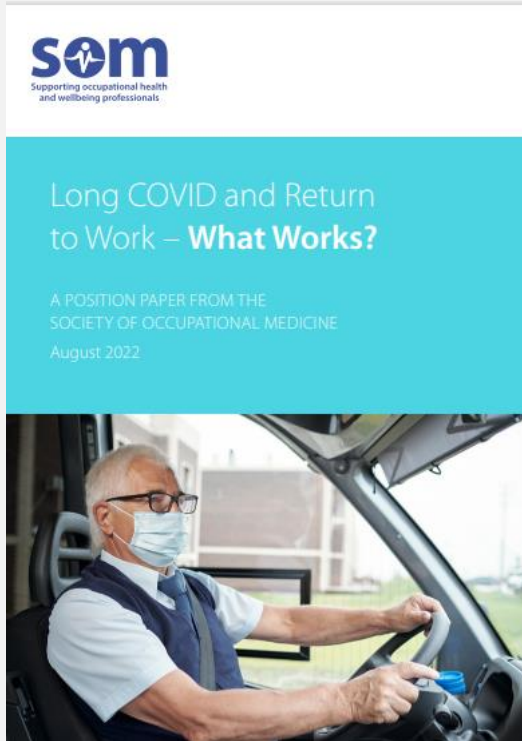
- Long, convoluted journeys
- Good LC teams if you can access them (post code lottery)
- Many LC clinics closing.
- Team HCPs vary but key professionals have been – physiotherapists, occupational therapists, psychologists, physician referrals where appropriate
- Good experiences when under a LC clinic, difficult when back with GP care
- GPs doing their best but limited and varying knowledge
- Everything is a battle

LONG COVID AND EMPLOYMENT: WHAT THE RESEARCH SAYS

- **Physical and Cognitive Limitations** – persistent fatigue, brain fog, chronic pain & worsening symptoms after exertion make it difficult for individuals to sustain usual work routines.
- **Reduced Working Hours or Job Loss** – many people with Long Covid have to reduce hours or leave employment.
- **Need for Workplace Adjustments** – returning to work requires phased reintegration, flexible schedules, & job modifications as well as a plan for symptom flare-ups.
- **Financial Hardship** – lost income, inability to work, and reliance on disability benefits create financial insecurity.
- **Emotional and Psychological Strain** – well-being impacted by work limitations, job loss, or the fear of losing job.

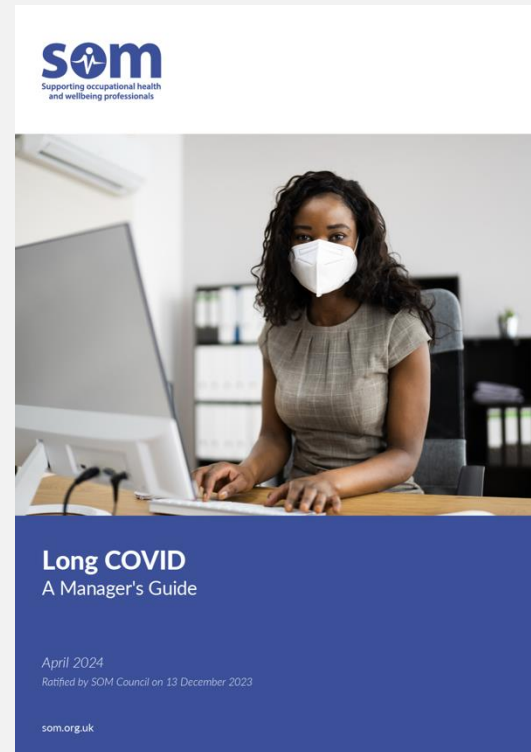
(Lunt et al 2022, Al-Aly et al 2024, Greenhalgh et al 2024)

SUPPORTING STAFF AND COLLEAGUES TO RETURN TO WORK: BEST PRACTICE GUIDELINES



Click [here](#)

YouTube video [here](#)



Available [here](#)

[Infographic](#)

[Myth buster](#)



[Advice for members](#)

[Advice for managers](#)

SUPPORT (OR LACK
OF) WHEN
RETURNING TO
WORK

No evidence
base/limited data
on what is
happening

We know a lot
from our service
users in the charity

Lack of
compassion in the
NHS system and
line management

Unrealistic
expectations of
return to work

Two failed return
to works and then
exit

Redeployment
rarely considered

Ill-health
retirement not
easy to navigate
with LC symptoms

WORKING IN THE NHS WITH LONG COVID: LIVED EXPERIENCE

Extended phased return not on offer

- Only offered standard 4 week return to work programme
- Having to use A/L to extend
- Lack of consistency

Unrealistic expectations

- Too many hours, too quickly
- Full time courses with 2 weeks of return
- Not able to work from home
- Many people can't work 12 hour shifts
- May not be fit to work in clinical practice

RETURNING
TO/STAYING IN WORK
- MICHAELA'S
EXPERIENCE

Felt rushed to return to work following being critically ill

Long Covid was only just being talked about

Had a phased return but was quickly overwhelmed

Spent the last 4 years in a cyclical situation of wearing a figurative mask at work so my symptoms aren't evident

Coming home to crash and feeling unsafe at times on my journeys home

Hybrid working has helped immensely

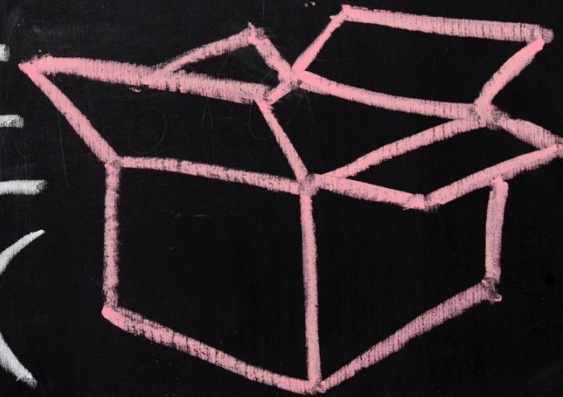
Needed to reduce my hours

Excellent disability plan and reasonable adjustments

Supportive line manager

SETTING
PEOPLE UP TO
FAIL

THINK
OUTSIDE
THE
BOX



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NON-EVIDENCE BASED INFECTION PREVENTION AND CONTROL GUIDELINES

NON-EVIDENCE BASED INFECTION PREVENTION AND CONTROL GUIDELINES

- Compelling scientific evidence indicates Covid-19 is airborne - as are most respiratory pathogens (Greenhalgh et al. 2021; Marr and Tang 2021; Morawska et al. 2024; World Health Organization (WHO) 2024a).
- UK National Infection Prevention and Control Manuals (NIPCMs) have not been updated to reflect this.
- Because of this inappropriate protective measures continue to be provided putting patients, staff and visitors at risk.

Scientific reasons which conclude COVID-19 is airborne

(Greenhalgh et al. 2021)

1 Superspreading events can only be explained by airborne transmission (inhalation of virus laden aerosols)

2 There is documented long range transmission between rooms – which can only occur with airborne transmission

3 Asymptomatic transmission happens, i.e. without spraying droplets

4 It is more an indoor disease than an outside one
Transmission indoors is reduced by ventilation.

5 Nosocomial transmission has arisen when droplet and contact precautions were well applied.

6 It was found in the air in the absence of AGPs – can only happen with airborne transmission

7 It was found in filters and ducts, places not reachable by droplets

8 Limited evidence for contact or droplet / sprayed on

9 It has spread between caged animals at distance and around corners – this can only happen by airborne transmission

10 Unrefuted by hypothesis

11 It spread over the 3rd 4th & 5th cinema screenings

12 It spread 5m backwards on a bus – without physical contact

13 It remained infectious in an empty room to infect after 4+ hours after non-occupation
Confirmed by WGS

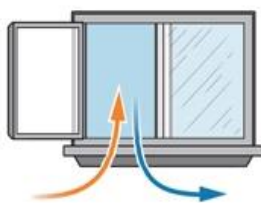
Ten scientific reasons in support of airborne transmission of SARS-CoV-2 - PMC (nih.gov)

Key findings and lessons from the COVID-19 pandemic regarding the reduction of viral loads through ventilation in the indoor environment (Morawska et al. 2024)



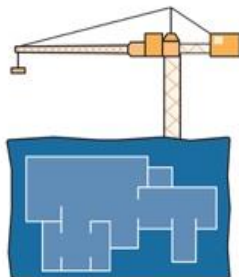
Lesson 1

Interdisciplinary expert knowledge should be the guiding factor in infection risk control and indoor air quality management in general.



Lesson 2

Ventilation must go far beyond advice to “open the window.”



Lesson 3

Better building designs that optimize ventilation performance, with indoor air quality as the focus, should be the guiding principle behind the construction of buildings in the future.



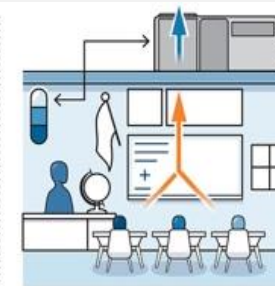
Lesson 4

Equivalent ventilation—for example, filter-based or GUV devices—is useful as a supplement in spaces without adequate ventilation.



Lesson 5

Ventilation control guided by risk assessment tools is unlikely to be a common (everyday) practice in the future. However, these tools have a role in building design.



Lesson 6

Ventilation performance should be monitored at all times when buildings are occupied.



Lesson 7

Indoor air quality must be regulated to protect human health in public spaces.

OUTDATED MODES OF TRANSMISSION

- UK National Infection Prevention and Control Manuals (NIPCMs) rely on an outdated **droplet-aerosol dichotomy** which defies physics.
- This false dichotomy leads to incorrect assumptions about transmission risk (Marr and Tang 2021).

No evidence has emerged to demonstrate transmission via droplets.

REVISED MODES OF TRANSMISSION

(Marr and Tang 2021)

Inhalation

Spray

Touch

Route of transmission	Protective measures
Inhalation	<ul style="list-style-type: none">• Respirators and masks with excellent fit and filtration capability along with ventilation and filtration to reduce transmission inhalation
Spray	<ul style="list-style-type: none">• Distancing and face shields to mitigate transmission by spray (where surgical mask and face coverings are also effective to some degree)
Touch	<ul style="list-style-type: none">• Hand hygiene, surface cleaning and gloves to reduce transmission by touch

PROTECTIVE MEASURES



**Supporting
Healthcare
Heroes UK**

#SafeAir4All Campaign

<https://shh-uk.org/making-the-invisible-risk-visible-indoor-air-quality-is-a-priority/>



UNSAFE AIR - LIVED EXPERIENCES OF HEALTHCARE SETTINGS

- Crowded departments, not always somewhere to sit
- Very close to the next person
- No-one but you wearing a respirator (mask)
- Often labelled as anxious because you are wearing a respirator (mask)
- Windows not open/can't be opened
- Lack of air circulation (poor ventilation)
- Using CO₂ to assess quality of ventilation in indoor areas

CO₂ AS A PROXY FOR INDOOR AIR QUALITY [\(Iwamura et al. 2024\)](#)

CO₂ and respiratory viruses are both exhaled.
If the CO₂ concentration in a room is high so is the amount of exhaled aerosol.

CO₂ concentration correlates with amount of exhaled aerosol in a room.

Portable CO₂ monitors are a useful tool for estimating the quality of ventilation in a room.

#SafeAir4All CAMPAIGN

Aim: to make the invisible risk of poor indoor quality visible

We're asking people to do **four** things



Step 1: Take photos

Take your CO₂ monitor with you to healthcare settings.

Take a photo of the meter reading.

Post the photo on social media with **#SafeAir4All** or upload it to our **.Padlet Board**



Step 2: Tell us your stories

Tell us about your experiences of infection prevention and controls measures while in a healthcare setting:
<https://shh-uk.org/padlet-safeair4all/>

**#SafeAir4All
CAMPAIGN**



Step 3: Contact your MP

Contact your MP in person, via email or letter.

Share a copy of our Fact Sheet with them: <https://shh-uk.org/wp-content/uploads/2025/06/mp-prioritise-indoor-paper.pdf>

**#SafeAir4All
CAMPAIGN**



Step 4: Put up copies of our poster

Print off a copy of our poster and put it up in the healthcare settings you visit.

The poster can be downloaded here:
<https://shh-uk.org/safeair4all-campaign-poster-now-available/>

**#SafeAir4All
CAMPAIGN**



ALISON'S ADVENTURE

Petition calling for the government to
introduce new indoor air quality and PPE
standards in healthcare settings



01

Become a trustee or volunteer

02

Participate in our #SafeAir4All campaign

03

Fundraise for us

04

Make a donation

05


Follow us on social media


WHAT CAN YOU DO TO HELP



Follow us on Social Media

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 @shh-uk.bsky.social

 /SupportingHealthcareHeroesUK

 @SupportingHH_UK

 /SupportingHealthcareHeroesUK

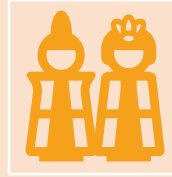
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