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Long COVID guidance for UKFRS



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COVID/Long COVID – guidance for UKFRS Employers

June 2021

Updated 5th August 2021

Purpose of the Document

To provide easy access to:

- Information about COVID-19 and post COVID syndrome, Long COVID
- Information about the extent of Long COVID in the general population and in the UKFRS
- Information about how to recognise the multiple symptoms of Long COVID
- How to support employees with the symptoms of Long COVID accessing support
- How to develop a supportive working environment for those experiencing Long COVID and able to work
- Where to get help and the bespoke support from The Fire Fighters Charity

What is COVID-19?

On 31 December 2019, the World Health Organization (WHO) was informed of a [cluster of cases of pneumonia of unknown cause](#) detected in Wuhan City, Hubei Province, China.

On [12 January 2020](#), it was announced that a novel coronavirus had been identified in samples obtained from cases and that initial analysis of virus genetic sequences suggested that this was the cause of the outbreak. This virus is [referred to as SARS-CoV-2](#), and the associated disease as COVID-19.¹

What is Long COVID?

- Highly debilitating for many sufferers, Long COVID is an increasingly widespread, multi-system condition. Regardless of the severity of their initial illness, it appears that anyone of any age – including children - can experience Long COVID.
- The term 'Long COVID' includes both ongoing symptomatic COVID-19 (5-12 weeks after onset) and Post-COVID-19 Syndrome (12 weeks or more).
- It is associated with a wide range of different symptoms impacting physical, psychological, and cognitive health.
- It can also influence quality of life and ability to work or attend education.²

How to determine Long COVID is the cause of symptoms

This guidance³ refers to patients who meet the clinical case definition of ongoing symptomatic COVID-19 and post-COVID-19 syndrome and is taken from the National guidance for post-COVID syndrome assessment clinics, in conjunction with The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) who have produced in December 2020 a rapid guideline on managing the long term effects of COVID-19.

This guideline set out the following clinical definitions:

- Acute COVID-19: signs and symptoms of COVID-19 for up to four 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.

¹ [COVID-19: epidemiology, virology and clinical features - GOV.UK \(www.gov.uk\)](#) accessed 24th June 2021

² Long COVID: the NHS plan for 2021/22 Version 1, June 2021 accessed 24th June 2021

³ National guidance for post-COVID syndrome assessment clinics Version 2, 26 April 2021 accessed 24th June 2021

- It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.
- Research published June 2021 identifies **respiratory** and **fatigue/tiredness** as primary symptom clusters at 12 weeks, however other symptoms are still reported.⁴
- Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.
- The term 'Long COVID' is also commonly used to describe signs and symptoms that continue or develop after acute COVID-19.
- It includes both ongoing symptomatic COVID-19 and post-COVID-19 syndrome

What are the symptoms of Long COVID?

- People with symptoms at 12 weeks essentially fall into one of two groups based on the symptoms they were experiencing are:
 - One group is characterised by respiratory symptoms like shortness of breath, tight chest and chest pain, and in this group more people had reported severe COVID-19 symptoms.
 - In the other group the predominant symptoms were tiredness often with muscle aches, and difficulty sleeping.⁵
- Other common symptoms include:
 - difficulty sleeping (insomnia)
 - heart palpitations
 - dizziness
 - pins and needles
 - joint pain
 - depression and anxiety
 - tinnitus, earaches
 - feeling sick, diarrhoea, stomach aches, loss of appetite
 - a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
 - rashes

Who is at risk of Long COVID?

- Long COVID can affect anyone, even those who are young, fit, and active. It can occur in individuals following either severe or relatively mild illness, it can occur in individuals who have been hospitalised and those who haven't. There have even been reports of cases of Long COVID where individuals were asymptomatic at the time of infection.
- Findings from the REACT-2 studies⁶ show over a third of people who had coronavirus (COVID-19) reported symptoms lasting at least 12 weeks.
- This amounts to 5.8% of the whole study population, with 2% reporting severe symptoms
- Prevalence of Long COVID increased with age and was higher among women
- Over 2 million people in England are thought to have had one or more COVID-19 symptoms lasting at least 12 weeks according to one of the largest studies of the virus funded by the government.
- The study is based on self-reported data from 508,707 adults aged 18 and above who took part in REACT-2 rounds 3 to 5 carried out between September 2020 and February 2021.

⁴ [New research shows 2 million people may have had long COVID - GOV.UK \(www.gov.uk\)](#) page 21-22 pre-print report accessed 24th June 2021

⁵ [Over 2 million adults in England may have had long COVID - Imperial REACT | Imperial News | Imperial College London](#) accessed 020821

⁶ [long covid paper draft \(imperial.ac.uk\)](#) accessed 24th June 2021

- Around a fifth of those surveyed reported having had a COVID-19 symptom previously, with over a third reporting persistent symptoms lasting at least 12 weeks. Around a tenth of those with symptoms said they lasted at least 12 weeks and were severe.
- The findings suggest prevalence of persistent symptoms, or Long COVID, increases with age, with a 3.5% increase in likelihood in each decade of life. It shows Long COVID is higher among women, people who are overweight or obese, who smoke, live in deprived areas, or had been admitted to hospital.
- Persistent COVID-19 symptoms were lower in people of Asian ethnicity.
- Convalescence study⁷ found that one in six (17%) middle-aged people who reported having had COVID-19 also reported long COVID symptoms.
- Estimating potential FRS workforce affected – could be based on total UK workforce and the estimated percentage of the community population (those not in hospitals, care homes or other institutional settings) that had COVID-19:
 - 1.57% (1 in 65 people) in England, up from 1.36% (1 in 75 people) last week
 - 0.62% (1 in 160 people) in Wales, up from 0.47% (1 in 210 people) last week
 - 1.48% (1 in 65 people) in Northern Ireland, up from 0.59% (1 in 170 people) last week
 - 0.94% (1 in 110 people) in Scotland, down from 1.24% (1 in 80 people) last week⁸

How is Long COVID diagnosed?

There is no definitive laboratory test for Long COVID. A diagnosis is based on medical assessment, usually by a history consistent with acute Covid-19 followed by a prolonged recovery, and exclusion of other possible causes of the symptoms. In essence Long Covid is being viewed as presenting with ‘*complexity*’ because of the many and various symptoms present after 12 weeks and but not necessarily, following positive Covid test, Long Covid is assumed if the background context fits and there are no other underlying conditions.

The current guidelines of the National Institute for Health and Care Excellence (NIHCE) recommend to further investigate coronavirus related symptoms that may persist beyond 4 weeks after the acute phase of the infection:

1. Ongoing symptomatic COVID-19 for people who still have symptoms between 4 and 12 weeks after the start of acute symptoms.
2. Post COVID-19 syndrome for people who still have symptoms for more than 12 weeks after the start of acute symptoms.

A positive test for COVID-19 is not necessary for the diagnosis of Long COVID. A diagnosis of Long COVID can still be made even if the individual didn’t have a positive Covid-19 test when they first became ill. At the start of the pandemic widespread testing was not available.

What causes Long COVID?

The exact cause of Long COVID remains unclear and there is ongoing research into this area. It is likely to be due, at least in part, to an inflammatory reaction and similarities have been drawn with other post viral syndromes similar to the after-effects of other viruses or an autoimmune response.

⁷ [Convalescence Long-COVID Study | COVID-19 Longitudinal Health and Wellbeing National Core Study - UCL – University College London](#) accessed 050821

⁸ [Coronavirus \(COVID-19\) latest insights - Office for National Statistics \(ons.gov.uk\)](#) accessed 020821

Impact of Long COVID

Many people who have long-term symptoms after coronavirus infection can continue life as usual however for some people there is a significant impact on their quality of life. The physical and psychological impact of Long COVID symptoms can adversely impact on all activities of daily living, from extreme tiredness, reduced exercise tolerance and restricted mobility through to difficulties with concentrating and memory, even carrying out simple tasks or communicating can be challenging. These debilitating symptoms can inhibit work effectiveness and prevent a partial or full return to work.

Long COVID is not a static condition, symptoms can change, improve, and relapse. The course of this illness is not predictable and may change from day to day

There is no 'cure' for Long COVID, nor is there any definitive treatment, the focus is on management of symptoms and rehabilitation.

A Note of Caution

There are conflicting views regarding the existence of Long COVID, in a similar vein to the controversy regarding CFS/ME, of which it is pertinent to be aware.⁹

The role of the NHS [Primary Care]¹⁰

General practice plays a key part in the Long COVID clinical pathway. Patients, with previously confirmed or suspected COVID-19, may present with a wide range of symptoms including breathlessness, fatigue, chest pains, cognitive impairment, or psychological symptoms. The initial role of the general practice clinician is to exclude acute or life-threatening complications and other unrelated diagnoses.

Assessment may include blood tests, chest X-rays or clinical tests, including sit-to-stand or lying and standing blood pressure, depending on the person's signs and symptoms (as per NICE/SIGN/RCGP guidance). Advice, treatment, or referral to the relevant acute or specialist services may be required.

Where an assessment in general practice identifies a mental health condition as the predominant symptom, support and/or treatment should be considered in line with existing local mental health pathways.

As symptoms can be relapsing and remitting, with new symptoms appearing, assessment may not be a one-off occurrence. All assessments, whether the first or on an ongoing basis, should be holistic and consider physical, psychological, and cognitive problems.

If ongoing symptomatic COVID-19 is diagnosed (from 4 weeks after infection), the patient may be offered the following:

- Signposting to self-management support including the online platform Your COVID Recovery (YCR) Phase 1 <https://www.yourcovidrecovery.nhs.uk/>
- Supported self-management from the practice or primary care network team; this may include input from social prescribers, health and wellbeing coaches and care coordinators with linking into community groups or other existing community services as appropriate
- Referral into a Post COVID assessment clinic if self-management alone is not appropriate and if further investigations or support are required.

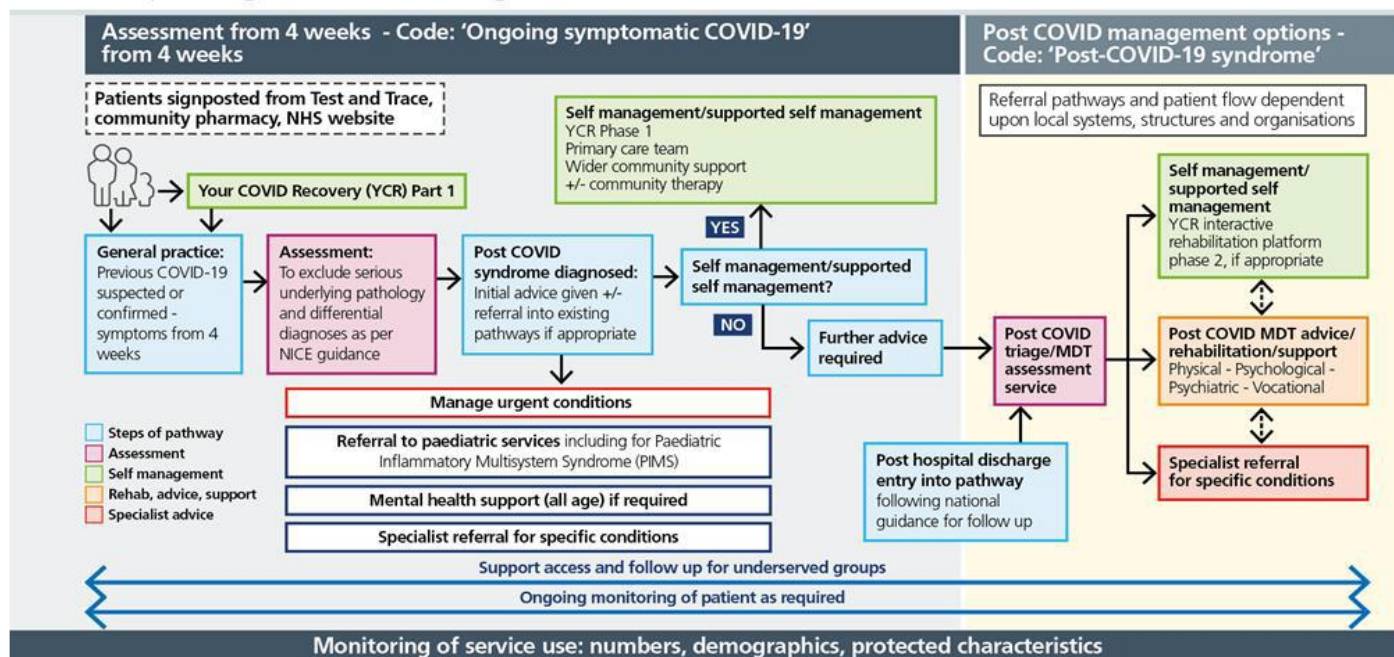
⁹ [Chronic fatigue syndrome and long covid: moving beyond the controversy | The BMJ](#) accessed 24th June 2021

¹⁰ [Enhanced service specification: Long COVID 2021/22 \(england.nhs.uk\)](#) published 24th June 2021; accessed 25th June 2021

NHS Clinical pathway for Long COVID

Primary/community care post-COVID syndrome pathway all ages

Incorporating NICE/SIGN/RCGP guidance 2020



The implications for employers

There are impacts of Long COVID that will affect the employer as well as the employee.

There is the issue of presenteeism, with people returning to work when they are not well enough to do so.

There is also the opposite issue of employees not being able to return to work for some time, and not knowing when they are likely to feel well again, which of course creates staffing issues.

The symptoms of Long COVID vary greatly from person to person but the one similarity is that it can be really debilitating, to a person's mental or physical health, or both.

Supporting an Employee with Long COVID¹¹

Recovering from long COVID can be a lengthy process and employees will need to be supported to recover at their own pace ensuring that they do not relapse. Line managers can support staff member with long COVID by:

- Having regular [wellbeing conversations](#) to see how staff members are feeling now that they have returned to work.
- Checking whether any employee that is working reduced hours and has a less demanding role are still happy with this arrangement and whether they would like to make any reasonable adjustments.

¹¹ [Supporting recovery after long COVID - NHS Employers](#) Accessed 25th June 2021

- Asking whether the employee is working flexibly to allow them time to adjust back into the workplace, working longer/ shorter days, taking longer breaks etc.
- Recommending that staff members join long COVID support groups and peer networks.
- Highlight wellbeing services and psychological support.
- Signpost staff to multidisciplinary post COVID rehabilitation clinics (where available) - staff can be referred via a GP or occupational health.

Supporting employees absent from work due to Long COVID

Line managers also need to be supported and guided on how they can manage and support their staff effectively while they are absent from work.

Line managers can review what support is already available to them in their organisation, which can be found in the section above (supporting staff at work with long COVID). Line managers may also want to ensure that they are:

- maintaining regular contact to support and connect with staff during their absence
- refer to local sickness absence procedures to ensure that appropriate principles are applied to support staff
- signpost to local support/ in-house services such as:
 - musculoskeletal and rehabilitation services
 - psychological services
 - wellbeing services
 - peer groups
 - staff networks
 - financial wellbeing advice
 - guidance on working from home
 - chronic fatigue services
- refer colleagues to an occupational health adviser to ensure they are supported as early as possible.

Working with Occupational Health to support employees with Long COVID

Occupational health may advise that the employee:

- is unfit to return to work and should continue to stay on sick absence with regular check-ins
- returns to work on a phased return with reduced hours allowing sufficient time for recovery
- does a less physically demanding role such as admin/ taking phone calls/ reducing their caseload that will allow them to work at a desk or in some cases from home
- does a less cognitively demanding role by considering job rotation and adjustments such as moving to a less cognitively demanding work area and reducing caseloads.

Facilitating safe return to work for employees with Long COVID

Employers should follow the [latest government guidance](#) to enable staff to work from home where possible. However, this may be difficult for some roles and employees.

Employees may be anxious about returning to the workplace after having time off sick with Long COVID and may require additional support from the service. This may include:

- holding [a wellbeing conversation](#) with the employee about how they feel about returning to work, to listen and support them with any anxieties and explore options to support a return
- giving the employee a less physically and emotionally demanding jobs
- having a conversation about working shorter hours or take longer more regular breaks
- allowing a return to work on a standard or extended phased return
- ensuring that conversations about returning to work are under constant review and that the employee feels comfortable about returning to work.

The Society of Occupational Medicine (SOM) has produced a [return to work guide](#) for managers on how they can provide ongoing support to employees to return to work following COVID-19 infection and Long COVID.

Phased return

Employees with Long COVID may benefit from a gradual return to work that can be adapted to everyone's circumstances.

Some may experience difficulty in being able to fulfil the physical, emotional and cognitive side of their role, therefore, the phased return may allow them to:

- work from home (when possible)
- work reduced hours
- work a more flexible working pattern, for example, three longer days instead of five shorter days
- take regular and longer breaks - research shows that short and frequent breaks are more effective
- reduce demands of their role
- work less cognitively demanding jobs if the employee is suffering from brain fog
- work at a desk if their current job is physically demanding, reduce physically demanding aspects of the job
- discuss opportunities to be redeployed.

For more information on a phased return NHS Employers' [Reasonable adjustments in the workplace web page](#) features a number of organisations, including government bodies, that have developed a range of good practice videos and guidance to help employers support employees.

The employer should regularly check in with the employee to ensure that this pattern of work is suited to them and explore if it is necessary to increase or decrease their workload

In essence, supporting an employee should:

- Take a personalised / individual case by case approach.
- Work with the employee to understand how it is affecting them and what support they need
- As well as the physical implications, consider the emotional, and psychological impacts of Long COVID. What makes things worse / what helps?
- Conduct individual risk assessments with employees who are experiencing symptoms of Long COVID and make reasonable adjustments where practicable.
- Extended phased returns are likely required along with more flexibility in any return-to-work plans.
- Consider Workplace adjustments such as:
 - Alteration in number of days or hours worked
 - Shorter days, more breaks, later starts or earlier finishes
 - Change of hours to avoid travelling at peak times

- Time off work to attend medical appointments
- Access to rest area
- Home working (for all or part of the working week)
- Phased return to work, gradually increasing the days/ hours worked over a period of several weeks
- Temporary transfer from night or shift working to regular daytime hours (if applicable)

How The Fire Fighters Charity Can Help?

Within the pathways diagram on page 6, the Charity provision sits to the far right, providing non-acute support in the form of self-management/supported self-management; a multi-disciplinary team approach to bespoke, individualised rehabilitation that integrates physical, psychological, and social health. The Charity is well-placed to provide such support because of the focussed approach and our unique understanding of the needs of the beneficiary workforce.

Working in partnership with services and beneficiaries – whilst maintaining our unique relationship with the beneficiary, we are providing a ‘Covid Recovery Programme’, a mix of residential and remote support through digital means.

The Fire Fighters Charity COVID Recovery Programme

Focus of the Programme

An individualised and bespoke programme, with person specific agreed outcomes to improve current health status, reduce risk of long-term illness and improve/reduce/manage the symptoms associated with Long-COVID, maximising function and potential for return to work.

Experience

The programme is a blend of residential and digital support, tailored to need, ability and capacity. There will be group activity as well as individual support, maximising the benefits of peer support whilst enabling individual privacy.

Beneficiaries will stay in one of our centres, the programme is starting at Marine Court but will be rolled out to other centres as demand required.

This is a new programme, that will evolve as knowledge about Long COVID increases. The Charity has established a research plan to underpin the programme, beneficiaries will be asked to engage with anonymised data collection with the view contributing to the national knowledge base on Long COVID, [engagement with the research is **not a pre-requisite** to accessing the programme].

Interventions – current June 2021

- Residential and digital support
- Tailored to meet beneficiary need

Residential Programme

- 1 week stay, full board and support, 5-day programme, with a follow up stay after 12 weeks.
- Multi -disciplinary approach – Physical Health, Psychological Health, Social Wellbeing /welfare
- Key components of the residential programme:

- Hydrotherapy
- Individualised exercise programme – pool and land based
- Knowledge of condition and coping techniques / health condition anxiety management
- Stress and health anxiety techniques
- Self-care and rest
- Trauma health education
- Nutrition, health eating and Weight Management
- Sleep management
- Pacing and fatigue and rest
- Guided Mindfulness/meditation
- Tai Chi
- Pilates
- Breathing techniques & normal breathing pattern training
- Loss, change and uncertainty
- Mind, body, health, and exercise

Psychological Support

- Drop-in sessions are available if required to support the group- based work within the residential programme

Digital Support

- On-line session prior to attending for residential stay
- The stay is then followed up with 6-fortnightly one-hour online practitioner led group sessions to provide peer support and explore the 'lived experience', alongside delivery of specific health and wellbeing coaching support
- Confidential consultation via 'Attend Anywhere'
- Exercise prescription via Salaso App
- Telephone and SMS contact and 'nudging'
- Resources on website, webinars
- Peer to peer support group

Welfare Support

- Access to welfare support and advice if required – drop in sessions
- Managing finances
- Home adaptations
- Understanding statutory provision and access to this
- Family support

Referral Process

- The Charity maintains a direct relationship with the beneficiary and does not recommend fitness [or not] for work.
- The Charity seeks to work closely with employers to ensure the best support is available and, in this respect, accept 3rd party referrals with consent of the beneficiary.
- Where a beneficiary makes a self-referral, the Charity would encourage, but cannot mandate, disclosure to the employer.
- Any information regarding the health and well-being status of the beneficiary may only be shared with the employer with the consent of the beneficiary.
- Contact via 0800 389 8820 or [Enquire about support - The Fire Fighters Charity](#)

Other Resources

[Long-term effects of coronavirus \(long COVID\) - NHS \(www.nhs.uk\)](https://www.nhs.uk)

[Supporting recovery after long COVID - NHS Employers](#)

Ends.