



## PRACTICE POINTER

## Work and vocational rehabilitation for people living with long covid

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## What you need to know

- Support patients to assess their current abilities at work compared with what they could do previously; they don't need to be 100% well to start the process of returning to work
- Going back to work too early after acute illness may be counterproductive; patients should not make hasty decisions around resignation or retirement in the early stages
- Use the fit note to help someone return to work, emphasising the need for flexibility to accommodate day-to-day fluctuations

Long covid is a complex, highly variable, and sometimes relapsing-remitting condition that may have profound impacts on a patient's wellbeing and ability to work.<sup>1</sup> Many people living with long covid are attempting to return to work, or stay in work, while learning to manage an emerging long term condition.<sup>2</sup> These challenges may be compounded by workplace burnout, fuelled by labour shortages, the psychological effects of the pandemic, widening inequalities, and global economic insecurity.

For some people, disabling symptoms lead to complete inability to work.<sup>3</sup> In less extreme cases, "work instability," which is a mismatch between patients' functional abilities and the demands of their work, can threaten employment if not addressed.<sup>4,5</sup> This may manifest as difficulties in executive functioning and communication which adversely affect those in roles where they are expected to deliver at optimum performance in high pressure working environments. Numerically, however, the greatest impact is on patients from underserved communities who face the multiple jeopardy of physically demanding, inflexible, and insecure jobs where they encounter hostile scrutiny and punitive disciplinary procedures from supervisors. This scrutiny, combined with fewer employment rights—such as little or no entitlement to sick pay, working cash-in-hand, or being self-employed—creates additional stress and anxiety, often exacerbating their symptoms.<sup>6</sup> They are also more likely to have comorbidities that are worsened by prolonged covid symptoms, further affecting job security.

Workers may be fearful of disclosing a health condition, taking sick leave, or requesting temporary adjustments to their role.<sup>7</sup> Employers facing staff shortages and financial uncertainties are less able to support workers with long term conditions. People who have been out of work for more than six months have a 50% chance of never returning to work; early

intervention can help some people successfully reintegrate into the workplace.<sup>8</sup> However, unlike other vocational rehabilitation programmes for different conditions, where much more information is known, long covid presents a unique challenge. The multitude of symptoms experienced by people living with long covid, and the often fluctuating nature of those symptoms, means there are gaps in our knowledge of the most effective strategies to support people back into work.

In this article we offer an overview of the impacts of long covid on people's ability to work, and the types of patient scenarios clinicians may encounter. We outline how clinicians can respond to questions patients ask about work, suggest resources, and appraise what we know while considering patient experience.

## How does long covid affect employment?

A person with long covid typically experiences a symptom or cluster of symptoms that limit their ability to perform work tasks in specific and general ways.<sup>9</sup> For example, fatigue may make driving or using machinery unsafe because of changes in focused and sustained attention, while autonomic dysfunction may affect a patient's ability to stand for a prolonged period. Additionally, the cognitive impacts of long covid can affect problem solving abilities and the capacity to make timely and safe decisions by synthesising complex information. Voice changes can restrict participation in meetings or on telephone calls. Furthermore, symptoms such as pain, sleep disturbance, anxiety, or post-traumatic stress disorder have a more general impact on a person's overall functioning, irrespective of the components of their work role (box 1).

## Box 1: Patients' accounts of how long covid has affected their work

From research interviews with people with long covid<sup>10</sup>

- "What has been most useful for me during that time is learning to pace myself and listen to my body. I experienced three or four significant relapses after feeling better and doing too much because I felt improved, and then one or two days later, I found myself in bed again."
- "I've got okay at judging how to compensate for the tiredness and exhaustion as a result of a call or a conversation, but even now that means [...] I couldn't be a head teacher in the morning and sleep all afternoon, that's just not feasible."
- "I think the biggest challenge, really, was getting them to understand initially what my symptoms are and

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trying to explain what I've been doing and how I've got to where I am.”

- “I'm going to cover up the dark circles under my eyes and put makeup on [...] and they look and they say, ‘oh, you look really well,’ and inside you're screaming ‘but I don't feel well, I don't feel the way I look.’”
- “I don't walk home because I'm just too tired after working; my husband picks me up and brings me home.”

## How big is the problem for patients returning to work?

General practitioners trying to deliver clinical services at a time of unprecedented demand have limited time and may overlook or de-prioritise assessing the impact of long covid on employment. In March 2023, in the UK alone, an estimated 1.9 million people believed that they were living with long covid, with 381 000 (mostly of working age) reporting that their ability to undertake daily activities has been “limited a lot.”<sup>11</sup> Among those of working age, 20% are on long term sickness absence, and 48% have reduced their working hours.<sup>7</sup> A population based study in the canton of Zurich, Switzerland, involving 672 people of working age infected with SARS-CoV-2 early in the pandemic, reported that 5.8% of people who developed long covid experienced an impact on their work.<sup>12</sup> These estimates may not accurately reflect the full impact of long covid on work status. In particular, people from marginalised communities are more likely to develop long covid and are less likely to be able to access health services.<sup>13 14</sup>

Below, we address questions about returning to work or remaining in work, which patients might ask. Because long covid presents in many different ways, and the variety of jobs people have, no high quality evidence is available for interventions to improve people's return to work in long covid. In answering these questions, we draw from our work in vocational rehabilitation for other conditions.

## When should people with long covid return to work?

Patients should maintain regular contact with their employer during the early phase of illness, and request workplace support (eg, referral to occupational health services) at four weeks of sickness leave, as the health related problems with work are less likely to resolve spontaneously after six weeks of absence.<sup>8</sup> Patients do not need to be completely fit to return to work, and setting goals around when to return can be a vital part of their rehabilitation. At a minimum, patients should understand what relieves or exacerbates their symptoms. It helps to establish a routine at home with a view to consistently carrying out activities of daily living without significant deterioration.<sup>15</sup>

Deciding when to return to work is also dependent on a person's financial situation. Signposting to relevant information around a phased return to work and financial support is helpful in enabling them to make informed decisions at the right time. This has been effective in other acute onset conditions, such as acquired brain injury,<sup>16</sup> although can be challenging for patients working in the informal economy. Rigid return-to-work schedules are not appropriate for a fluctuating condition such as long covid.<sup>2</sup>

## What do patients say works best?

At present, no randomised controlled study evidence supports strategies for direct return to work in long covid. Instead, our practice based guidance has been informed by insights from people living with the condition, who have shared the most effective measures for a successful return to work<sup>17</sup>:

- Rest in the initial stages of acute covid-19 infection

- Obtain early advice on how to self-manage using pacing strategies that can be practised at home and consolidated in work. These might include planned rest breaks or avoiding consecutive working days
- Participate in peer support groups within and outside the workplace<sup>14 18</sup>
- Take advice on workplace rights and employment law through a union representative
- Arrange an initial face-to-face assessment with an occupational therapist or work coach, with tailored follow-up based on needs-led duration and frequency
- Plan a longer than usual phased return that accommodates fluctuating health and work capacity, and flexibility to work from home where possible to avoid commuting
- Ask at the long covid clinic for a leaflet explaining the condition that can be given to line managers and co-workers.

Box 2 outlines useful interventions for specific concerns.

### Box 2: How to support patients who face challenges returning to work

#### Returning to work with ongoing symptoms

- Reiterate that good work is important for wellbeing<sup>19</sup>; however, returning too early without careful planning poses a real risk of limiting recovery<sup>20</sup>
- Help the person identify demands of their work on a typical day and compare this with their current abilities
- Encourage setting realistic work related goals, considering timing of return to work and in what capacity
- Suggest that patients replicate some aspects of their typical workday to assess readiness. They may feel tired initially; encourage them to be alert to symptoms getting worse
- Encourage patients to record how they feel alongside what they are doing
- Advise a graded plan to return to work, with very small increments each week that do not exacerbate symptoms. Review this plan regularly.

#### Sickness absence for more than six weeks

- Encourage patients to maintain contact with their line manager, as this is the most effective way to prevent long term absence<sup>18</sup>
- Signpost patients to information resources for employers and long covid support groups.<sup>18</sup>

#### At risk of losing job and unable to work

- When referring to a long covid clinic, highlight the patient's need for early work support
- Signpost patients to the Advisory, Conciliation, and Arbitration Service (ACAS), a union, or Access to Work (the UK government programme aimed at supporting disabled people to remain in work) for support with travel or adaptations
- Use the fit note to support the role that work has in recovery
- Signpost patients to equality advisory and support services should substantial disability lasting 12 months or longer be likely, or discriminatory treatment be raised. No precedent exists to define long covid as a disability, but there are already some employment tribunals in the early stages
- Encourage patients who have not yet returned to work after their initial infection to inform their employer early of their intention to return to their original jobs, including any support they may need and any referrals that have been made for therapy. Ensure all correspondence

with employers is in writing and verbal conversations are summarised via email.

#### Unable to sustain work

- Validate the patient's experience that returning to work can be stressful and lead to undesirable outcomes, while acknowledging that some factors are beyond their control
- Encourage intervention from occupational health, human resources, or long covid clinic occupational therapy
- Support patients to be their own advocates by considering adaptations to their roles to facilitate conversations with managers; signpost to long covid advocacy groups
- In case of ill health dismissal, encourage the patient to complete the ill health dismissal process rather than handing in notice, as this may affect their ability to claim certain benefits.

#### Patient considering leaving work

- Encourage patients not to make impulsive decisions and explore phased returns or temporary changes to their role. Once an employee leaves an organisation, the employer has no further responsibility to provide support
- View the fit note as a solution-focused intervention to support adaptations needed to keep the patient in work
- Inquire if annual leave or unpaid leave could provide thinking time or break up the working week
- Reducing hours or leaving work can be a positive decision, so assess the situation and provide support to leave work well if this is the case. Encourage consideration of other activities, such as volunteering
- Up to 16 hours per week of "permitted work" is possible while claiming employment support allowance, so it may be feasible to reduce working hours with additional financial support. Note that the Job Centre should always be consulted before commencing permitted work

#### Patient considering ill health retirement

- Patients may consider ill health retirement, especially if this was being explored before their illness. Financial circumstances and type of pension scheme are key determinants in deciding whether this is advisable. Encourage patients to seek independent financial advice through a union or from an independent financial adviser
- Ill health retirement usually requires a medical assessment through an occupational health physician, and would include consideration of what a meaningful retirement may look like—how would the person fill their time? What is important to them now? How important are things like structure or making a contribution?

#### Patient experiencing financial difficulties

- For patients likely to experience ongoing substantial functional difficulties for 12 months or longer, refer to the Citizens Advice Bureau for support accessing employment support allowance, universal credit, or personal independence payments
- Signpost patients to a debt charity or local food bank, gov.uk website for benefits advice, Citizens Advice Bureau, local authority, or Department of Work and Pensions website.

## Questions from patients

### Are there any medical conditions that require treatment before I return to work?

Some clinical scenarios warrant further exploration, and possibly treatment, based on current clinical guidelines.<sup>1</sup>

- Chest pain requires investigation before undertaking any work that requires physical exertion, as there is a small but significant

risk of a life-threatening emergency if the pain is due to acute myocarditis.<sup>21</sup>

- Post-exertional symptom exacerbation is a characteristic feature of long covid, where symptoms markedly increase 12-48 hours after physical or mental activity, and if inappropriately managed can worsen disability.<sup>22</sup>
- Hypoxia or disproportionate tachycardia on exertion may be symptoms of autonomic dysfunction, or (much more rarely) pulmonary emboli, which require medical investigation and management before patients can return to a physically demanding work role or commute.<sup>23 24</sup>
- Changes in cognitive ability require a thorough cognitive assessment if the person has relevant symptoms and their role is safety critical, for example, a train driver or anaesthetist.<sup>25</sup>

### Should I return to work my usual hours and duties?

Immediately returning to usual hours, especially full time, after severe illness and prolonged absence (defined as six weeks or more) may lead to relapse and further sick leave.<sup>2</sup> Patients are likely to benefit from a phased return to work, with sustained flexibility around start times, rest breaks, home working, and productivity expectations. The general practitioner can support by starting this discussion with patients, and providing appropriate and specific guidance backed up by detailed fit notes. Supporting people with long covid in this way helps to validate their experience and mitigate further harm. Patients may further benefit by having their return-to-work plans reviewed regularly—weekly tends to be best—with someone, such as a line manager, who works closely with the employee.

In general, for greater periods of work absence, return to work should be longer and slower. For more complicated returns, after a very prolonged absence, or for a worker in a safety critical role, refer for vocational rehabilitation with an occupational therapist and a workplace occupational health assessment. If these are not available, and an employer is persisting in making a person return to work before being ready, then sick leave should be extended.

When discussing a return-to-work plan, suggest that the patient meets their line manager face to face (in person or in a video call) to agree a personalised plan.<sup>19</sup> An updated workplace risk assessment, or a stress risk assessment, may be required, depending on the work role and current psychological wellbeing. Understanding workplace policies can be overwhelming, and a union representative, if available, may be needed in the meeting to state clearly the employer's duties. Referral to Access to Work for support getting to and from work, or workplace adaptations, can be helpful.

### How much do I need to tell my manager?

Patients do not have to disclose health details to their employers, but it is helpful to inform their line managers what they are able to accomplish and what they find difficult. Specific arrangements, entitlements, procedures, and resources that exist with respect to medical leave are highly country specific. For instance, GPs, nurses, pharmacists, occupational therapists, or physiotherapists in the UK can use fit notes to frame some of these discussions in a positive, solution focused way. Table 1 gives some examples that can be included in a fit note.

Table 1 | Examples of workplace adjustments\*

Workplace modification	Example
Timing	Adjust starts and finishes to avoid busy commuting times Later start times if sleep is poor Adjust breaks to optimise energy
Hours	Shorter days to build up stamina Days off between work days
Working patterns	Regular and/or additional breaks
Shifts	Consider suspending late or early shifts or night duty
Workload	Fewer tasks than normal within a timeframe More time to complete tasks and processing written information Not being required to work to tight deadlines
Tasks	Temporary changes to duties or tasks, eg. removing heavy physical lifting or pushing
Providing additional support	Buddy system to check in with, or work alongside Additional supportive supervision of performance Regular wellbeing reviews Time off for appointments and therapy Additional training if work practices have changed since the illness first began Adjusting how information is provided, eg. bullet points Discretion around usual sickness management policies, acknowledging that sickness is to be expected with a fluctuating condition
Location	Working from home Virtual attendance in meetings, rather than physical Desk space on ground level Working in a quieter location
Aids and equipment	Voice to text software Headset provision Optimal seating Remote meeting software

\* Adapted from: COVID-19 return to work guide for managers: 2021 The Society of Occupational Medicine. [https://www.som.org.uk/sites/som.org.uk/files/SOM\\_Long\\_COVID\\_A\\_Manager%27s\\_Guide\\_Feb\\_2024.pdf](https://www.som.org.uk/sites/som.org.uk/files/SOM_Long_COVID_A_Manager%27s_Guide_Feb_2024.pdf)

Some people report that they feel stigmatised in relation to their long covid. “Working with long covid” guides (box 3) can be shared by patients with their employers to increase their understanding of the condition.

### Box 3: Services for patients in the UK to get further support and advice

- The Advisory Conciliation and Arbitration Service (ACAS) is an independent body that can provide support if your patient is in conflict with their employer. For potential employment tribunals, your patient will need to contact ACAS to inform them that a claim will be submitted to an employment tribunal within three months: <https://www.acas.org.uk/>
- The Equality Advisory and Support Service (EASS) helpline can provide independent advice around discrimination and the applicable law, especially when this is more than local services can provide. <https://www.equalityadvisoryservice.com/>
- Access to Work is a government scheme which will consider the provision and funding of aids, equipment, services, and transport to work, including for those who are self-employed. <https://www.gov.uk/government/publications/access-to-work-fact-sheet>
- The Federation of Small Businesses can offer advice to small and medium sized employers: <https://www.fsb.org.uk/knowledge/fsb-infohub/workplace-wellbeing.html>

### Does my manager have to follow the fit note advice?

The fit note has an “advisory” status only, therefore employers have the right to decide whether a recommendation would be reasonable or not, based on the feasibility and impact of the adjustment. A person would be deemed not fit to work if an employer is unable to

fulfil the specified recommendations, and the fit note should be updated to enable the patient to access statutory sick pay.

### My manager says I may need to be redeployed. What does this mean?

Redeployment means transferring to a different job role; it can be permanent or temporary. Temporary redeployment can be useful when adjustments have not been successful and can help by reducing work pressures and switching to duties that can be paced in a more structured way. Permanent redeployment should involve the agreement of both parties, following a defined pathway; further advice can be sought from a union.

### I am self-employed/work for a small or medium sized enterprise, what help can I get?

Smaller employers tend not have in-house occupational health services, but any organisation can access such support from a local occupational health service on a contractual basis to provide specialist support to the employee.

In the UK, people working for themselves can apply for Access to Work in addition to financial benefits, such as Universal Credit, if their business is their sole income. This scheme can offer support for people in a wide variety of freelance roles, such as contributing to the cost of equipment, travel, or a personal assistant. Entitlements can be checked using a benefit calculator through the Citizens Advice Bureau. Other resources to consider include the Federation of Small Businesses for access to business protection insurance, financial expertise, and health support.

## Resources for employers and employees returning to work with long covid

- Society of Occupational Medicine. COVID-19 return to work guide for managers. [https://www.som.org.uk/COVID-19-return\\_to\\_work\\_guide\\_for\\_managers.pdf](https://www.som.org.uk/COVID-19-return_to_work_guide_for_managers.pdf); [https://www.som.org.uk/sites/som.org.uk/files/Long\\_COVID\\_and\\_Return\\_to\\_Work\\_What\\_Works.pdf](https://www.som.org.uk/sites/som.org.uk/files/Long_COVID_and_Return_to_Work_What_Works.pdf)
- The Chartered Institute of Personnel and Development Long Covid hub. <https://www.cipd.org.uk/knowledge/cipd-knowledge-archive/#gref>
- The Chartered Institute of Personnel and Development Guide for line managers to support employees with long covid: Providing information to employers around what long covid is, how to manage and support someone with long covid, using the IGLoo model. <https://www.cipd.org.uk/knowledge/guides/long-covid-guides-people-managers/>
- The University Hospitals of Derby and Burton NHS Foundation Trust. <https://www.youtube.com/watch?v=beKcWMLGpc4>

## Guidance for patients on accessing financial benefits

- Advice Local is a website offering location specific guides to welfare benefits, council tax, debt, housing, employment, health, and social care. <https://advice.local.uk/>
- A guide written for long covid occupational therapy by Jenny Ceolta-Smith incorporating advice from GMLaw. <https://longcovidoccupationaltherapy.files.wordpress.com/2022/06/long-covid-and-personal-independence-payment-pip-complete.pdf>
- Citizens Advice Bureau. Can help managing bills, debt, housing, legal issues, and check eligibility for benefits (using a benefit calculator). <https://www.citizensadvice.org.uk/>
- Information on permitted work. <https://www.gov.uk/government/publications/employment-and-support-allowance-permitted-work-form/permitted-work-factsheet>

## How patients were involved in the creation of this article

The LOCOMOTION quality improvement collaborative included patient contributors. Patient led research was considered on equal terms with professionally led studies (and many authors were in both categories). Patients contributed the comments in [box 1](#). The paper was read by two additional people with long covid and modified in response to their feedback. The final version was read and approved by the LOCOMOTION Patient Advisory Group.

## How this article was created

This article, like others in this series on persistent symptoms following covid-19, aims to update and extend a previous *BMJ* Practice Pointer published in August 2020 at a time when there was almost no peer-reviewed research or evidence based guidance on the condition.<sup>26</sup> This paper draws on three sources. First, we conducted a literature search of PubMed using the search terms (coronavirus OR covid 19 OR post-covid) AND (vocational rehab OR return to work). We screened articles from 2020 to 2023. Second, we undertook research interviews with people with lived experience of long covid and professionals involved in long covid care.<sup>10</sup> Third, we asked experts in the vocational rehabilitation and occupational health communities for consensus statements, guidelines, service specifications, and patient facing literature.

<https://www.bmj.com/sites/default/files/attachments/resources/2016/03/16-current-bmj-education-coi-form.pdf>

Contributorship and guarantor: The paper draws on the clinical experiences and feedback from the LOCOMOTION consortium. All authors contributed to the literature search and synthesis of key findings from these. RJOC wrote the first draft which was amended by AP with contributions from the other authors. Members of the LOCOMOTION Patient Advisory Group read and commented on the paper, revising it for clarity and accuracy. All authors read and approved the final manuscript.

Manoj Sivan, Brendan Delaney (co-chief investigators), and Trisha Greenhalgh conceptualised LOCOMOTION and lead the study's workstreams. The authors thank patient research participants for the descriptions in [box 1](#), and Patient Advisory Group members: Sophie Evans and Jenny Ceolta-Smith. Thanks are extended to Emily Hide, GP link worker based in the Leeds Long Covid Community Rehabilitation Service for reviewing the paper from a general practitioner perspective. Trisha Greenhalgh reviewed a near-final draft of the manuscript.

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