CIPD

WORKING WITH LONG COVID

Research evidence to inform support

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Report

Working with long COVID: Research evidence to inform support

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Acknowledgements

(1) Introduction

This report examines the latest evidence and the experiences of employees experiencing long COVID, and offers recommendations for organisations on how to effectively support those with long COVID to return to, and stay in, work. In order to provide timely and appropriate support it is necessary to develop a deeper insight into the experience of long COVID in the workplace.

In this report, we integrate findings from three sources to understand long COVID and its impact on work:

- a review of the evidence on long COVID and its impact on work

- interviews with workers with long COVID

- a series of roundtables with HR professionals and allied health professionals involved in the support and rehabilitation of people with long COVID.

We report on common experiences, highlight differences between perspectives where these arise and bring together recommendations shaped by those who are currently navigating work with long COVID and those supporting them.

Long COVID shares characteristics with many other long-term health conditions, both in relation to the symptoms experienced and the impact on day-to-day activities. While this allows us to learn from the management of other long-term health conditions, there are some distinct considerations which are also examined in this report.

This report provides important evidence to help organisations understand more about long COVID as a long-term fluctuating health condition. It includes insights from individuals who have direct experience of the condition, as well as the views and learnings from HR, health professionals and managers on the measures that can best support people to manage their symptoms and stay in work. The key findings from the report will be translated into CIPD practical guidance and advice for HR and line managers.

(2) What is long COVID?

The COVID-19 pandemic has had a significant impact on the way we live and work. To date, energy and resource has largely been directed to reducing the risk of COVID-19 spreading in the workplace. However, the prevalence and impact of long COVID is emerging as a significant concern and needs ongoing attention from people professionals.

NICE defines post-COVID syndrome or long COVID as *'signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis'*. In terms of prevalence:

- One in five people experience symptoms lasting between 5 and 12 weeks.

- One in ten people experience symptoms after 12 weeks or longer.

- An estimated 1.3 million people (1.9% of the population) were experiencing self-reported long COVID as at October 2021.

Some groups are more likely to experience ongoing symptoms of COVID-19. The prevalence of self-reported long COVID is greatest in:

- people aged 35–69 years, although prevalence among those aged 17–24 is notably increasing

- women

- people living in more deprived areas

- people working in health or social care

- people with another activity-limiting health condition or disability.

Common symptoms of long COVID

We are still learning about the true impact of long COVID on an individual's physical and mental health. The three most common debilitating symptoms reported are fatigue, breathing issues and cognitive dysfunction, that is, memory loss, brain fog and concentration difficulties and speech.

Commonly reported symptoms include:

- fatigue
- breathlessness
- brain fog and poor concentration
- short-term memory loss
- slurred speech
- chest pain
- muscle and joint pain
- headaches
- sore throat
- vertigo
- hair loss and changes

- digestive difficulties
- autoimmune conditions
- insomnia
- heart rate changes
- blood pressure changes
- loss of taste
- loss of smell
- menstrual changes/early menopause
- poor skin
- depression
- anxiety

Symptoms vary between individuals, are overlapping and affect multiple systems in the body. Further:

- Symptoms can be unpredictable and fluctuate over time, characterised by periods of recovery and sudden relapse (sometimes with new or different symptoms).

- Mild symptoms can be followed by new or severe symptoms that impact on someone's ability to perform day-to-day tasks.

- Relapse is common; 85% of people with long COVID report that their symptoms had deteriorated after a period of improvement. Relapse can be caused by physical activity, mental activity, stress, heat and alcohol, and for some there is no identifiable cause.

- Symptoms can last for many months, and recovery can be slow and gradual over many months.

Importantly, many people report that their symptoms improve with time. The National Institute for Health Research has recently allocated nearly £20 million across 15 research projects to improve understanding of long COVID and identify effective treatments, of which the benefits to diagnosis and treatment will be realised in the coming months.

The number of people experiencing ongoing symptoms following a COVID-19 infection will likely increase over the coming months and years. Supporting these individuals to return to, and remain at, work will be an ongoing concern.

(3) Why long COVID is an important workplace issue

Long COVID shares characteristics with many other post-viral syndromes and long-term health conditions, both in relation to the symptoms experienced and the impact on day-to-day activities. While this allows us to learn from the management of other long-term health conditions, there are also some distinct considerations:

- Individuals with long COVID have experienced the uncertainty that comes with a new condition; this includes no clear diagnostic criteria, treatment or management plans.

- The volume of people experiencing a new condition at the same time is unprecedented.

- The broader pandemic context in which individuals with long COVID are unwell and seeking treatment and support – where home, healthcare and workplace resources have been persistently challenged and depleted – is unique.

This requires organisations to adapt their health and wellbeing plans and policies to take these unique circumstances into account, while continuing to adapt their support as we learn more about this new condition.

There are many compelling reasons why we need to consider the impact of long COVID in the workplace. As a new condition, people with long COVID often face a period of great uncertainty as they await diagnosis and an effective management plan. For those who are in employment, there is the double burden of uncertainty regarding how best to navigate their work. This has implications for sickness absence and return to work.

Sickness absence and long COVID
In the Patient-Led Research Collaborative report of 3,765 respondents with long COVID, 45% reported that they were working reduced work schedules and 22% were not working due to their health condition. In a TUC survey of 3,557 workers with long COVID, 57% had returned to work fully with 16% returning to reduced hours. While further research is required to understand the true workforce impact of long COVID, these findings have implications for how absence is managed, how employees are supported to return to and stay in work, and how they are enabled to leave work well (should work no longer be sustainable).

Very little is known about how many people have taken sickness absence due to long COVID, how long their absence has lasted or how it has been managed by their organisation. The severity of symptoms varies greatly, as does the length of sickness absence. So too does the employees' feelings towards their sick leave. Here, we share the work patterns and experiences of our interviewees and roundtable participants.

Some people describe being bedridden and unable to do simple tasks, like sit at a table to eat, let alone work. For this group, being absent from work is seen as necessary. Others describe feeling able to negotiate day-to-day tasks but suffer from bouts of fatigue that limit their ability to fully participate in work and therefore have not returned to work. Among this group, many feel frustration that they are unable to contribute.

As is common for many people with fluctuating health conditions, people with long COVID describe that the number of days taken as absent due to their condition has triggered formal absence management processes or disciplinaries. The TUC found this in 18% of respondents, while 4% reported that they had taken additional unpaid leave to avoid taking further sick leave. As a result of the amount of absence taken, 4% described being threatened with disciplinary proceedings, of which 1% translated into disciplinary action.

Some of our interviewees experiencing long COVID described taking annual leave to avoid this disciplinary action, for example :

> *'And that's what I have done to get through this. So I've been taking my annual leave to get a rest basically.'*
> **Employee working in education**

Returning to, and staying in, work with long COVID

Many people with long COVID return to work and thrive, while some require appropriate support and work adjustments to do so. Diverse return-to-work experiences were described by our research participants, with some reporting clear alignment with good practice principles, including:

- early communication

- flexible, slow and gradual return-to-work patterns

- ongoing support from colleagues and managers.

Others described poor practices, such as returning to a full workload, returning despite feeling unwell, missed return-to-work meetings and no work adjustments. It was notable that many interviewees described working when unwell, finding in retrospect they would have benefited from prioritising recovery. Many roundtable participants involving HR noted the damaging effect of presenteeism on those with long COVID.

> *'Progress has been up and down, I was doing an hour and then having to take two days off to recover at the beginning. So it was really very, very slow. And now I'm at the point where I can do much, much more and be productive, but I'm still only me. I went in yesterday, and I was there for two hours, and then came home. And that was about it. That was all I could manage.'*
> **Healthcare worker**

> *'People are not working well, the internal ableism – pressured by the individual, and society, to do as much as you can as quickly as you can. We need to allow people to return much more gradually and take time off when they need it.'*
> **Occupational health practitioner**

Why long COVID needs to be incorporated into absence management and support

For employees with long COVID:
- <u>Good work is good for health</u> and can reduce health and economic inequalities.

- Work can be a pathway to recovery, helping the individual maintain a sense of normality, and financial independence.

For organisations:
- Long-term sickness absence is a persistent problem for organisations and presents a major public health and economic concern.

- Where employees are not supported and exit the workforce, this presents a significant loss of talent. With the current skills shortages in many sectors, this has implications for recruitment and training costs.

For HR professionals:
- HR professionals are responsible for ensuring a sustainable and supported return to work and the implementation of effective work adjustments for employees; because long COVID is a new and complex condition, there is a need to consider whether existing practices are sufficient.

- HR professionals are also responsible for recruitment and retention practices. Long-term absence and turnover significantly adds to the burden of work.

For government:
- With a tightening labour market and skills shortfalls, public policy needs to factor in the risks of potential large-scale absences and turnover across the economy. These are particular concerns in the health service where long COVID is most prevalent.

- Long COVID is having a disproportionate impact on groups already disadvantaged in terms of work and health. Urgent support is required to limit further health and economic inequality for those affected.

- The longer people are off work, the less likely it is that they will return. The economic consequences for the welfare state of not adequately supporting those with long COVID to return to, and stay in, work is significant.

- Long COVID provides an opportunity to review and respond to the needs of people working or seeking to work with ill health.

Supporting employees with long COVID is therefore of potential benefit to individuals, organisations and the economy.

④ Insights and recommendations

This report provides insights into both the employee experience of working with long COVID and of the professionals working in HR, employment support and healthcare who are supporting them. The impact of long COVID on many employees is significant. Most notable is that, while everyone is doing the best they can, the lack of precedent for this new condition at a time of great flux has led to additional barriers for employees with long COVID.

What is evident is that many of the concerns raised are not new. Many thousands of employees with long-term health conditions have experienced similar challenges, and progress to put in place co-ordinated work and health support has been slow. What is different, however, is the very fluctuating nature of the condition, with a myriad of symptoms occurring in unpredictable patterns. This, alongside the novelty of the condition, makes it different from many other long-term conditions in terms of self-management and achieving a smooth return to work. These factors place a sharp focus on the urgent need for significant and systemic change in the way that people with health conditions, including long COVID, are supported to stay in work.

Here we synthesise the themes identified from three roundtable discussions with 43 professionals working in HR and allied health professional roles, and interviews with 14 individuals who had returned to work with long COVID. We explore the diverse mix of pressures and barriers that those returning to work with long COVID face and the resources they can draw upon to support a successful and sustained working life. Based on these, we put forward recommendations at each of the IGLOO levels (outlined below) to encourage a whole-system approach to better supporting employees with long COVID. It is important to note that while these recommendations are specific to employees working with long COVID, they are likely to be of benefit to those working with other long-term conditions or navigating other life challenges to return to, and stay in, work.

IGLOO framework

IGLOO is used as a framework to explore the barriers and facilitators to support individuals with long COVID returning to, and remaining at, work. The IGLOO framework was originally developed to support employees returning to work after a period of ill health. The whole-system approach to supporting individuals in work promotes a shared responsibility where everyone has a role to play: the **I**ndividual employee, the **G**roup, **L**ine manager and the **O**rganisation, and **O**utside resources.

IGLOO level	Definition within this study
Individual	The employee diagnosed or yet to be diagnosed with long COVID.
Group	Colleagues or team members of the employee with long COVID.
Line manager	The line manager with people management responsibility for the employee with long COVID.
Organisation	The wider organisation; for example, HR, resources, work practices, occupational health provision.
Outside	The support and services available outside of the organisation, including healthcare and charities.

Within each level, there are attitudes, behaviours and actions that can act as facilitators or barriers to returning to work. In understanding these barriers and facilitators, we will be better positioned to support employees returning to work with long COVID.

Individual

There are many things an individual can do for themselves to support their return to work. At the individual level, a range of barriers and facilitators were described by research participants as impacting the return to work of employees with long COVID.

Barriers/challenges (factors that hinder or get in the way)	Resources/facilitators (factors that support and assist in return to work)
• Denial or unaware of difficulties	• Acceptance of reduced work functioning
• Trying to do too much too soon	• Self-discipline in pacing a slow recovery
• Hiding the true extent of individual symptoms or difficulties	• Openness in discussing ability to perform/function in role – could be embedded in the performance management approach
• High or unrealistic expectations for recovery	• Lowering expectations of ability to perform the whole job as before during recovery
• Mental health impact: sense of loss and grief, feeling a burden, sense of helplessness	• Self-compassion: showing kindness and care to themselves during recovery
	• Understanding their employment rights and how to exercise them

Key recommendations to improve individual support

To support individual employees working with long COVID return to and thrive in work, we recommend that organisations:

- provide clear and accessible information on employment rights

- encourage employees to be open and honest about how their symptoms hinder them at work by being explicit about the impact their reduced function can have on performing specific work tasks

- encourage people to pace themselves and conserve their energy to reduce the likelihood of relapse

- provide access to advice and training on self-management strategies to help them better manage the symptoms of long COVID and their work.

Group

There are a number of things colleagues and team members can do to support an individual return to work. At the group level, a number of barriers and facilitators were described by research participants.

Barriers/challenges (factors that hinder or get in the way)	Resources/facilitators (factors that support and assist in return to work)
• Lack of knowledge and understanding of long COVID and its impact on an employee's work	• Understanding and knowledge of long COVID and how it might impact the employee and their work
	• Practical support from colleagues, such as stepping in to help with a task
	• Taking conversations or tasks at the employee's pace
	• Emotional and social support in work
	• Outside work activities
	• Proactive approach to managing team wellbeing and not just for the long COVID returnee

Key recommendations to improve group support

To enable the group members to support employees working with long COVID return to and thrive in work, we recommend that organisations:

- provide access to education and training to increase the understanding and awareness of long COVID and how it might impact work. This could be part of a wider guidance and training programme about working with disabilities and long-term health conditions

- monitor team members' workload if a team member is absent from work or working reduced hours. Ensure team members have the capacity, competence and resources to provide practical and compassionate support to employees with long COVID

- prioritise wellbeing at work among the team through regular check-ins, wellness action plans and putting wellbeing on the team meeting agenda throughout the year.

Line manager

Line managers play an <u>important role</u> in supporting employees to return to work. At the line manager level, a number of barriers and facilitators were described by research participants as impacting the return to work of employees with long COVID.

Barriers/challenges (factors that hinder or get in the way)	Resources/facilitators (factors that support and assist in return to work)
• Lack of knowledge and understanding of long COVID and its impact on health and work	• Understanding of long COVID and how it might impact the employee's health and their work
• Over-promising and under-delivering on the flexibility or support available	• Confident and empowered to understand and interpret policies surrounding return to work and workplace adjustments
• Returning the individual to full workload and work tasks	• Phased return and work adjustments
• Seen as 'damaged goods' so not functioning as they were before	• Flexible approach, responsive to work functioning day to day
• A one-size-fits-all approach to supporting an individual with long COVID	• Individualised work adjustments developed with the employee
• Sharing information about the employee without consent	• Seeking consent from the individual about what information is shared about their condition with their colleagues/team
• A lack of formal or timely diagnosis provides a reason not to provide support or work adjustments	• Being symptom-led rather than diagnosis-led when considering work adjustments
• Impatience for the individual's performance and productivity to be restored to pre-long COVID levels	• Being patient and flexible during relapses and setbacks
	• Making time to have regular and consistent wellbeing checks and ongoing discussions

Key recommendations to improve manager support

To enable line managers to support employees working with long COVID, we recommend that organisations:

- train line managers in supporting employees to return to work following sickness absence and implement work adjustments

- provide guidance and training to increase line managers' understanding and awareness of long COVID and how it might impact work, with a specific emphasis on the line manager's role and responsibilities. This could be part of a wider guidance and training programme about working with disabilities and long-term health conditions and could include upskilling in the key line manager behaviours identified through CIPD research to promote wellbeing at work

- ensure line managers are provided with discretion to operationalise the absence management policy in a compassionate way.

Access to work adjustments are important for employees with long COVID. In a study by the Patient-Led Collaborative, 45% of people with long COVID described how working from home had enabled them to continue to work, specifically through reducing the additional burden of commuting and increasing the flexibility of working hours.

Interviewees with experience of long COVID and roundtable participants noted a number of work adjustments that were helpful in supporting employees with long COVID return to work, including:

- offering home or hybrid working
- flexible working times
- reducing commuting time
- being creative and flexible when exploring work tasks or job roles that an individual could perform
- making work tasks physically, mentally or cognitively less demanding
- having access to a wellbeing room for downtime during the working day
- working within a supportive organisational culture.

However, access to work adjustments was not universal and many participants described barriers to accessing them, as well as to the ongoing implementation of work adjustments. These findings are aligned with the TUC findings: while 44% of those employees who asked for changes to their job reported that these had been made, a further 31% reported that only some of the changes had been made, with 8% reporting no changes had been made.

Organisation

Organisational policies, practices and stakeholders can impact employees' return to work. At the organisational level, research participants described a number of barriers and facilitators.

Barriers/challenges (factors that hinder or get in the way)	Resources/facilitators (factors that support and assist in return to work)
• Rigid and inflexible absence management and return-to-work policies	• Absence management processes that are flexible and supportive to accommodate fluctuating conditions
• Lack of expertise or influence from occupational health	• Expertise and support from occupational health
• Lack of knowledge and understanding	• Understanding and knowledge of long COVID and how it might impact the individual employee and their work
• Perception that some work environments or job roles don't lend themselves to phased returns	• Flexible and creative approach to work adjustments and return to work for all roles
• Lack of capacity to support employees returning with long COVID, in the wider context of HR professionals prioritising returning the whole workforce, following official government work-from-home advice	• Contact and guidance from HR professionals during the return process
• Organisations making a distinction in the way absence management policies are applied during diagnosis versus once a diagnosis is secured, leading many to take annual leave or work when sick during the diagnosis phase	• Being symptom-led rather than diagnosis-led when considering work adjustments
	• Company culture that embraces inclusion
	• Access to quiet spaces, for example wellbeing room
	• Workplace support groups, for example wellbeing champions group
• Not recognising individuals have lives outside of work that they also need to preserve their energy for	

Key recommendations to improve organisational support

To support employees with long COVID return to and thrive in work, we recommend that organisations:

- review <u>absence management policies</u> and the organisation's framework to support employees with <u>long-term health conditions</u> to ensure that they are flexible, compassionate and based on individual need as far as possible

- provide access to occupational health services in a timely and accessible way

- provide access to financial education to help employees manage the challenges of reduced income

- ensure that leaders within the organisation understand long COVID and its potential impact on employees and their interaction with work, and the wider organisation

- create an open and inclusive work climate that fosters supportive discussions about work and health.

Outside

A number of factors outside of the organisation were also found to facilitate or frustrate the employee's ability to work and their return-to-work-journey. While these are beyond the control of the organisation, they are noteworthy, given their impact on the ability of the employee to access the support and guidance that they need to recover, and therefore resume and sustain work.

Consistently, in our research, employees with long COVID and those supporting them noted significant challenges surrounding the pathway to diagnosis. The lack of timely or accurate diagnosis often meant that employees were on waiting lists for some time within the healthcare system.

The value of external support was raised by all research participants. Every region's healthcare system has different services; however, access to occupational health, occupational therapy, physiotherapy, long COVID clinics, vocational support, psychological therapies, charities and, most notably, the Long COVID Support group were identified as valuable sources of support and guidance for returning employees.

Key recommendations to mitigate outside factors

To support employees with long COVID return to and thrive in work, we recommend that organisations:

- ensure that key stakeholders, particularly line managers, are aware of, and compassionate about, the delays in securing a diagnosis and rehabilitation support as these are very likely to be beyond the control of the employee

- ensure that the employee and those who are supporting them in work are aware of the range of support available from the Government and local charities, for example, support through England's Improving Access to Psychological Therapies programme (IAPT), Access to Work, and the Long COVID Employment Support group.

(5) Conclusion

Many employees with long COVID face a triple burden:

- The absence of clear rehabilitation pathways as healthcare specialists continue to learn about the condition means that employees are on an uncertain journey.

- Colleagues, friends and family members, line managers and HR professionals are depleted and preoccupied with other matters due to the pandemic. This means that many employees with long COVID may be receiving less support than those who experienced long-term illnesses pre-pandemic.

- The pressure on the healthcare sector, combined with the high volume of people seeking diagnosis and support for long COVID, means that many people experience long wait times for diagnosis and treatment.

As the pandemic continues, it's vital that organisations enable the facilitators in the IGLOO framework set out here. Applying this framework will help them to overcome the barriers that many employees with long COVID encounter, and put them in a much better position to support people to return to, and stay in, work productively and safely. The recommendations in this report are mutually reinforcing and, if implemented at all levels of the organisation, will significantly enhance an individual's ability to manage their symptoms and thrive at work. While HR professionals may not be able to directly influence what happens outside their organisation, there are a wide range of practical actions they can take to limit the long-term impact of the pandemic on our workforce.

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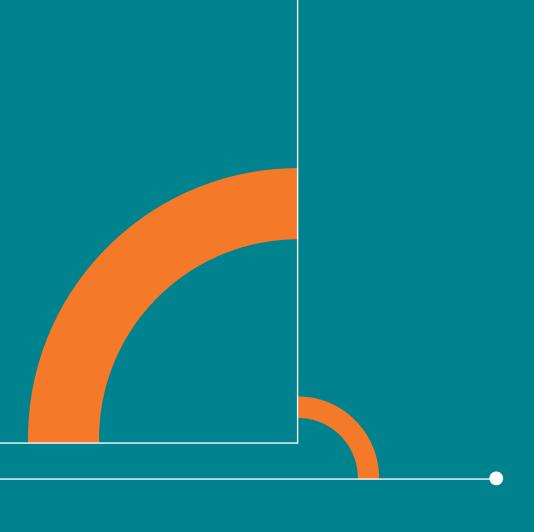
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