Written evidence from Long Covid Support to the Work and Pensions Committee: Disability Employment (DYE0058)

April 2024

About Us

Long Covid Support

Long Covid Support is a charity registered in England and Wales. Our private peer support group has over 65,000 members from 100 countries and continues to grow daily. We have a dedicated Research Involvement group that links patients and professionals together resulting in co-produced published evidence and experts by lived experience PPI. We advocate for health, research, and workplace support and prevention of job loss. We have co-produced events and resources with professional bodies such as NHS England, National Institute for Health and Care Clinical Excellence (NICE), National Institute for Health Research (NIHR), Trade Union Congress (TUC) and The Society of Occupational Medicine (SOM) and provided evidence to parliament, government, and healthcare bodies since the early months of the pandemic in 2020.

We welcome this opportunity to present our written evidence to the Committee, and our focus is on people with Long Covid. Due to the nature of our illness, we have only been able to address one of your questions in detail: **How can people with disabilities and health conditions be better supported to start and stay in work?**

We have listed key areas of concern (as red flags) in the final section which may address some of your other inquiry questions.

We want to draw your attention to the latest research that has centred on employment issues for people with Long Covid and other research that captures this theme. These publications capture earlier data; however, we know this research holds strong relevance in 2024. We also refer to unpublished research from the LOCOMOTION NIHR study that two of the authors (Dr Jenny Ceolta-Smith and Dr Clare Rayner) have had patient research advisory roles in.

It is important to note that the barriers to paid work that we cover are not uncommon for disabled people especially those with fluctuating, episodic conditions including energy limiting conditions. Therefore, our submission is likely to have wider relevance, and this includes people with Myalgic Encephalomyelitis (ME). Of key importance with the identified barriers is the limited recognition, acknowledgement and understanding of Long Covid amongst many stakeholders.

We draw on our insights from our peers captured in our lived experience and advocacy since 2020. We have attempted to represent our wider Long Covid UK community by seeking lived experience examples from our peers in Facebook groups, social media,

and direct contacts. This written evidence submission builds on our first submission to you in 2021: Employment Support (DES0008) and Long Covid Support's and Long Covid Work's (this group is no longer active) written and oral evidence to the Works and Pension Committee for: Plan for Jobs and Employment Support (JES0065) in October 2022. Therefore, we have purposefully omitted any details included there such as the definitions of Long Covid, and the impact this condition has on peoples' daily lives and work ability.

We remain concerned that despite having the ongoing UK COVID-19 inquiry lessons have not and are still not been learnt about the prevention of COVID-19 and reinfections. We have many people with Long Covid who have been ill since early in 2020 as shown in the latest ONS figures April 2024 with some people, like Mike below having been out of work for many years:

> "*I exist, I don't really have a life", Mike said.*
> *"I haven't worked since October 2020. I've had three failed attempts to get back to work… but I just couldn't do the job."* From: https://www.bbc.co.uk/news/uk-england-leeds-68627548

The urgent priority need is to prevent and treat Long Covid remains.

We disagree with stakeholders who refer to the pandemic in the past tense and any focus on supporting people into paid work must ensure that workplaces are meeting their legal requirements on health and safety which must include mitigating against contracting COVID 19 and reinfections. We signpost you to our past submission for further details and have included key references below on clean air.

Key issues for people with Long Covid who are returning to work, trying to stay at work, must exit work and plan to re-enter work.

In this section we detail many of the barriers to work for people with Long Covid and identify potential solutions. We structure this section around five key themes.

First, we would like to show how the impact of Long Covid symptoms (over 200 found in research) have been described in the literature to:

- Fluctuate
- Relapse-remit
- Wax and wane
- come and go over time
- sometimes get better and sometimes worse.

Long Covid has been found to be an activity limiting or energy limiting condition and an episodic disability.

We want to emphasize the individual nature of how Long Covid may impact a person's daily life and ability to undertake paid work or not, and therefore a one size approach to employment support is unsuitable. This is crucial to understand within the context of any employment support provision that is currently being delivered or designed for

people with Long Covid. Of particular concern is any support delivered by non-healthcare professionals i.e. work coaches as there may be contraindications and risks to peoples' health and recovery to the support they suggest.

Worryingly we see a recent call for research, for example by Professor Trisha Greenhalgh to study 'long long covid' as many of us with Long Covid have now suffered with this condition since 2020. Please see the ONS data April 2024 which reported that there are an estimated 2 million people in England and Scotland experiencing self-reported Long Covid, with nearly a third experiencing symptoms for at least three years.

Defining working and not working while living with Long Covid

While a range of definitions are in use for official data collection purposes to categorise people who are not in paid work, we observe that many people in our Long Covid community dislike the use of economic inactivity with some having a preference to use unemployed.

Figure 1 illustrates some of the driving and restraining forces that people with Long Covid may experience when preparing and returning to paid work.

Driving forces can include:

Financial need (e.g. inadequate or no sick pay)

Wanting to work

Valuing career

To re-establish a routine

To support mental health

To keep a current job

Receipt of PIP to support a reduction in work hours

Support from OH/ occupational therapist

Agreed reasonable adjustments (and Access to Work and accommodations)

Supportive manager

Guilt over feeling that they are "letting colleagues down" by being off sick

Paid work (Part time /Full time)

Restraining forces can include:

Poor health

Too ill

Unable to carry out essential activities of daily living

No access or delayed health care interventions

Poor quality healthcare and psychologization not diagnosed or delayed in diagnosis

Unsupportive workplace policies

Unsafe workplace with no clean air/ no Covid19 mitigations and risks of being reinfected with COVID 19

No suitable roles e.g. when needing to be redeployed

Poor line management

Other roles such as caring must take priority

Five key themes for people with Long Covid associated with barriers to employment.

1. **Access to effective healthcare and early intervention**

Barriers:

- Many people with Long Covid report that they have experienced no significant support by a Long Covid clinic, for example, they have been discharged without any improvement to enable a return to work.
- Long NHS waiting lists for specialty services if referred.
- Problems accessing specialist healthcare professionals in fields including occupational health (OH) (which also includes occupational therapists working in OH), occupational therapy and vocational rehabilitation practitioners.
- Accessing GP appointments in some areas that are timely and supportive.
- We are unsure about what is happening to Your Covid Recovery and where people will get advice on work.

Solutions:

- Ensure the SOM guidance is being followed See below in key resources section.

- Ensure stakeholders are supported to learn, upskill, and build on best practice e.g. from the NIHR LOCOMOTION study outputs. See here.

- Ensure that professional organisations such as the Royal College of Occupational Therapists disseminate new research for learning and transferring findings to practice. For example, new tools such as the NIHR LOCOMOTION Vocational Rehabilitation Roadmap to both members and non-members, their specialist interest group for work and the Vocational Rehabilitation Association. See Parkin et al. 2024 and Link here.

- Ensure people with Long Covid can access specialist services for their health needs. within our peer community there is a lack of clarity on what is happening to Long Covid clinics in England See here.

2. Recognition, and supportive individualised responses to people with Long Covid in all workplaces and workspaces

Barriers: Misunderstanding, disbelief, and disregard of the impact of Long Covid on a person's work ability from stakeholders including line managers, HR departments and colleagues This barrier is often attributed to the invisible/hidden nature of many Long Covid symptoms.

> *"There is still a complete lack of understanding […] from the management [at work], and colleagues and it's the hidden disability thing, completely […] the fact that…I don't look like I need support'*. (Person with Long Covid Anderson et al. 2024)

Solutions:

- Mitigating factors include support from OH to support people to make their disability more visible to their employers for example, while working remotely as found in Anderson et al. 2024.

- Targeted sharing of the key documents see below that can support stakeholders in return to work.

Barrier: Stigma related to the disclosure of having Long Covid in the workplace

- In the joint TUC and Long Covid Support survey: Workers' experiences of Long Covid N= 3,097 in 2022, one in eight (12 per cent) said they did not inform their employer of their Long Covid symptoms.
- It is common for us to hear from people who have started new jobs to choose not to disclose they have Long Covid and therefore may miss out on any reasonable adjustments and provision for example, from Access to Work that they need.

Our insights chime with Clutterbuck et al. 2024 who revealed how a participant in their qualitative study "(Male, 60–69, White) suggested that if he was looking for a new role, he '*might keep it [Long Covid] to [himself]' to avoid negative views preventing him from finding employment.* "(p,9)

Solutions:

- To explore ways in which people with Long Covid can be supported to talk to an employer about their disability.
- In our advocacy we promote the use of a Health passport (A tool that can help a worker identify what support might be of benefit to them in their role) and this is documented in the SOM manager's guide and LOCOMOTION Vocational Rehabilitation Road map. (see below). We are aware that the NHS has its own version: https://www.nhsemployers.org/publications/nhs-health-passport and other versions exist for example, the Reasonable adjustment disability passport via the TUC However, we do not know how effective such tools are and how widely used it might be. The CIPD note that that although UK organisations don't often use health passports when they are used they are '*broadly effective':* Therefore, there may be some value in seeking stakeholders' views about these tools and educating employers/line managers.
  https://www.gov.uk/government/publications/health-adjustment-passport

Barrier: Uncertainty of stakeholders– is Long Covid a disability?

- Some employers are not considering Long Covid as a disability under the Equality Act 2010.
- People with Long Covid often raise questions about whether they are deemed disabled in the Equality Act 2010 and entitled to reasonable adjustments. We hear from many people that they have not been given reasonable adjustments or only some of the support advised e.g. via OH or Access to Work has been agreed by their employer. Examples include not being permitted to work from home or agreeing to coaching sessions.

Uncertainty about Long Covid and disability by workers has been revealed in Clutterbuck et al.'s 2024 p 9 study too:

"*It's not considered a disability ... you could just be fired just like, you're not performing. And you go, well, I've got Long Covid. They go ... we're not legally obliged to consider that so, tough*. (Male, 30–39, White) "

We also know that some healthcare professionals lack understanding about the Equality Act 2010 and therefore do not consider this in their practice.

This uncertainty is of considerable concern especially when the agreement for reasonable adjustments has shown to be key in supporting someone with Long Covid to return to work as shown in the case study below.

A number of tribunal cases have now tested and confirmed the definition of Long Covid as a disability, but crucially the Equality and Human Rights Commission has clarified that tribunals are not needed to prove that Long Covid is a disability*.

As the TUC points out "Tribunals *are a last line of defence and form of recourse for when a worker has been treated unlawfully, not a route to be treated lawfully in the first place. In addition, whilst tribunals are an important form of justice there are a significant number of barriers in taking a case to tribunal for all workers, let alone someone experiencing the symptoms of Long Covid."* TUC and Long Covid Support 2023).

Long Covid falls nearly within section C (Long-term) of the UK government's *Guidance on matters to be taken into account in determining questions relating to the definition of disability* (2011) and specifically section C5-C18 on Recurring or fluctuating effects and C9-C10 on likelihood of recurrence.

Barrier: **Discrimination**

The joint TUC and Long Covid Support survey, Workers' Experiences of Long Covid, 2023, revealed that two-thirds (66%) of workers with Long Covid have experienced unfair treatment at work. One in six workers with Long Covid reported having been subjected to bullying and/ or harassment, for example being ignored or excluded, singled out for criticism or excessive monitoring of work.

Almost three in 10 (28 per cent) respondents said they were concerned Long Covid has affected their chances of a promotion in the future and 15 per cent told us their colleagues or manager have questioned their commitment to their job.

"Told not to go for promotion in case I draw attention to myself and my illness (even though we agree I meet the criteria for promotion)." Woman, 46–55, education] (TUC and Long Covid Support 2023).

Almost a quarter of respondents (23%) said their employer has questioned whether they have Long Covid and/or the impact of their symptoms. Respondents reported facing disbelief and typical misunderstanding of energy-limiting illnesses that assume that people are just tired and should push through this tiredness (while research shows that Long Covid fatigue has a physiological cause related to mitochondria dysfunction, that pushing through it worsens everyday functioning and exercise is detrimental) See here.

"My boss questions my symptoms - said it seemed like a lot of symptoms for one person, as if I was lying." (Woman, 46–55, education.) (TUC and Long Covid Support 2023).

"[My manager] does not fully understand the impact of LC and therefore has made comments which suggest she feels it is equivalent to her own tiredness etc and that I should therefore be able to 'push through'." (Woman, 36–45, education.) (TUC and Long Covid Support 2023).

As well as a range of discriminatory treatments detailed in the report and its case studies (see page 6) One in seven (14 per cent) of respondents said they had:

- been forced to take early retirement
- felt forced to resign to protect their health
- felt forced to leave their job for other Long Covid related reasons or;
- felt they had been singled out unfairly for redundancy.

Altogether, one in seven respondents to the joint TUC and Long Covid Support survey (2023) of more than 3,000 workers with Long Covid, have lost their jobs directly because of having Long Covid.

It is notable from the survey that the reasonable adjustments for returning to work and to support staying in work that are granted by managers differed from those that people with Long Covid needed and requested. The adjustment most frequently granted (more often than requested) was a phased return to work - but employers are making assumptions that at the end of the phased return the worker will beat their previous healthy capacity and fit to resume normal duties. This is evidenced by adjustments to duties and requests for flexibility to manage symptoms being, by contrast, more frequently requested than granted. (TUC and Long Covid Support 2023).

The survey showed that longer and more frequent breaks and flexibility to manage symptoms were the reasonable adjustments most frequently requested by workers to enable them to return to work and continue working with Long Covid - but not as frequently granted.

Solutions

- **ACAS provide guidance on this matter,:**

"*Long covid is still a new condition and it may take time to understand it fully. It can affect a person's day-to-day activities and it's currently understood that it can last or come and go for several months, even years. The effects of long covid could also cause other impairments. Long covid could be a disability, depending on how someone is affected by it. Employers should focus on the reasonable adjustments they can make rather than trying to work out if an employee's condition is a disability."*

But we question whether this guidance is enough.

Training for stakeholders to include healthcare professionals, union representatives, managers and colleagues is essential. It is vital that employers, healthcare professionals, union representatives and anyone involved with assessing health capability is trained and duty bound to familiarise themselves with the guidance to the definition of disability in the Equality Act 2010. And that they specifically are trained to understand Section C - the definition of Long-term in that guidance, that covers recurring conditions a.k.a. episodic disability.

This is necessary to prevent disability discrimination and avoid creating healthcare, support, and employment barriers for people with Long Covid who are disabled by the condition, as per the definition of long-term disability in the Equality Act 2010. The subsections below are key:

C5 The Act states that if an impairment has had a substantial adverse effect on a person's ability to carry out normal day-to-day activities but that effect ceases, the substantial effect is treated as continuing if it is likely to recur…Conditions with effects which recur only sporadically or for short periods can still qualify as impairments for the purposes of the Act, in respect of the meaning of 'long-term'

C7. It is not necessary for the effect to be the same throughout the period which is being considered in relation to determining whether the 'long-term' element of the definition is met. A person may still satisfy the long-term element of the definition even if the effect is not the same throughout the period. It may change for example, activities which are initially very difficult may become possible to a much greater extent. The effect might even disappear temporarily. Or other effects on the ability to carry out normal day-to-day activities may develop, and the initial effect may disappear altogether.

Workers with Long Covid need to be listened to by employers when they tell them what reasonable adjustments they need to stay in work - and these steps should be recognised as reasonable adjustments for a disability.

Barrier: Unfit for purpose workplace policies

Anderson et al.'s 2024 UK qualitative study involved interviewing 65 participants found that "*current sickness absence, return to work and welfare policies are disabling and unfit for purpose, requiring participants to take sole responsibility for the additional 'rehabilitative work' involved in returning to employment*."

Solutions:

- We hope that the new statutory right to request flexible working will make a positive difference.
- See case study B for a good example of an employer adopting a flexible approach to return to work which also includes hybrid working and redeployment.

Barrier: The return to the pre pandemic standard phased return to work

We hear that many employers have not only failed to take on board the need for extended and gradual phased returns to work but have reverted to usual pre pandemic practice. For example, we hear that the NHS policy now offers a standard 4–6-week approach rather than a prolonged flexible and tailored to an individual's needs. This standard type of phased return is unlikely to be successful or result in workers being able to return to their full duties, risks worsening their condition, or leaving work prior to any capability processes being put into place. So essentially it is setting people up to fail.

'*There's a 6-week Return-To-Work policy in the NHS and you're supposed to be back up to your full hours within 6 weeks; it just doesn't work, so it's probably why we're haemorrhaging staff*…" Quote on X Twitter by a doctor who is seeing patients with Long Covid.

3. Re-entering the labour market

Barriers:

- A lack of accessible (e.g. one stop place to go to) and up to date information for all stakeholders on how best to search for and start new work including self-employment for people with Long Covid. E.g. The Government website has not been updated since March 2023 See here. So, for example, this link does not have the updated SOM guide for managers Feb 2024.

- People with Long Covid are unsure of what support is available to them to support a return to paid work which might be self-employment too.

- A lack of suitable jobs and suitable hours
- A lack of trust in the Jobcentre and work coach role especially given the Government's and media's demonisation of disabled people and people with health conditions
- No named work coach if a person is claiming New Style ESA in the support group.
- Poor communication methods e.g. with delays in DWP's telephone phone line and written correspondence response following letters being sent by claimants.
- Little awareness of permitted work options for people in receipt of New Style ESA (As discussed in our last submission)
- Risks associated with permitted work e.g. we know a few people with Long Covid have had their New Style ESA Benefit suspended or stopped because they have exceeded the earning threshold by a small amount.

In our WCA consultation response to the DWP we wrote: "*Given the complexity of Long Covid and ME/CFS, it is not safe or appropriate for Jobcentre work coaches (or other frontline staff in the Department's contracted provision) to make discretionary recommendations about tailored work preparation activities. Work coaches and disability employment advisors are unqualified, and untrained for such tasks and may cause pwLC or pwME unintentional harm*".

Solutions

- Build appropriate and safe approaches to integration with healthcare professionals e.g. in Long Covid clinics with local Jobcentres to enable voluntary engagement at the right time that is safe for people with Long Covid.

- Potential to explore the feasibility for a claimant to have an opt-in light touch meeting with a work coach or disability employment adviser at agreed periods of time e.g. 6, 9 or 12 months if in the support group.
- Education for stakeholders about permitted work and ensure people are supported to understand the rules about this.
- Explore what flexibility DWP decision makers can offer if a claimant exceeds the earnings threshold by a minor amount to prevent having to leave their job through additional stress of having lost their benefit.
- Creation of the suitable jobs (we are aware of current research by Catherine Hale and colleagues and other academics for example, on hybrid working, see below)
- Wider national awareness and training on the impact of Long Covid but importantly to involve stakeholders with lived experiences in such initiatives.

- We don't know if disability employment advisors or work coaches are specialising in Long Covid in each Jobcentre locality. If not, this may be of benefit. In addition to any approaches the Jobcentre is undertaking to developing networks with local occupational therapists in primary care for example. However, we expect such initiatives will take place with the new Work Well provision and include multidisciplinary working.
- Disability Confident- we don't know if this is making a difference for people with Long Covid (but we do known some people have not been supported by disability confident employers) We are aware of the updated report by CIPD in April 2024

We hear from many people with Long Covid who are confused about the rules and processes of claiming benefits. Some people are put off from claiming and therefore are unlikely to access DWP support. Worryingly some people with Long Covid are being required to attend in person to the Jobcentre for example when claiming Universal Credit despite having a Fit Note and they are struggling to attend these appointments. But people are not aware of the need to raise a request for a reasonable adjustment, for example to have a phone call with a work coach at home rather than a face-to-face meeting in a jobcentre. Face to face attendance may compromise a claimant's health and recovery. It may exacerbate their condition too. These current ways of delivery suggest that some work coaches have limited understanding of the impact of Long Covid on a person's daily function. In addition, many people with Long Covid need to pace and manage their activities often termed as their 'energy envelope'. This approach is central to the self-management of Long Covid symptoms, but it is not a cure, and is challenging to do and can still lead to unpredictable symptoms. We are concerned and disappointed that this crucial level of understanding is not recognised by the DWP in many areas of policy and delivery e.g. in medical assessments such as the WCA and PIP and the Jobcentre.

4. Staying in work, supporting recovery and being as well as possible

Barriers: Sustaining work

There is limited evidence about people with Long Covid sustaining paid work. But we know that an increasing number of people who have had to leave work after numerous COVID 19 reinfections See case study C.

The case study in the joint TUC and Long Covid Support report: Workers' experiences of Long Covid March 2023 provide an example of a worker who needed two years in his job to be able to return to full time working.

Lower quality of Life: Research shows people with Long Covid have a lower quality of life. Many people who are working full or part time hours report that they give everything they have to work and then must rest on the days they are not working. This need for rest means for example, they cannot socialise, go shopping, prepare healthy meals, tidy the house, and often say they are living to work. Therefore, if someone is working from home, they may be quite isolated which is not good for their mental health.

Solutions

- Clean air and COVID 19 mitigations see below.
- Ongoing regular reviews of a worker's return to work plan are crucial see SOM document below e.g. to ensure sustained flexibility and that all accommodations and reasonable adjustments needed are in place.
- A need for employers to plan for ongoing periods of workers' sickness absence See Nielsen and Yarker 2023 too:

'*A couple of times I've had to say I need to go home because of this ... I feel like I'm taking the Mick [not taking work seriously] myself*'. (Male, 50–59, Asian) Taken from Clutterbuck et al. 2024 p9)

- Review of workplace policies.
- Signposting to PIP which can support a person with Long Covid to use energy conservation measures.

5. Uncertainty of re-entering the labour market

Barriers:

People can find it difficult to know how to approach finding work after a long period of sickness and job loss. These barriers are not just in terms of the labour market, e.g. in searching and applying for jobs but knowing when it might be possible to start work again, in what type of role and for how many hours.

Some people have told us they have lost their confidence while being off work particularly if this period has been over a few years. This finding is also shown in the research by the LOCOMOTION study (Parkin et al. 2024)

We know some students who were unable to finish their studies degrees, masters PhD or had only recently qualified (some having significant debts to repay too). There appears to be limited support for some people with Long Covid to complete their studies.

One of the key barriers is the number of hours some people with Long Covid may be able to work for.

Solutions:

- Support to engage in safe activities that may support someone's recovery and move closer to returning to paid work for example, volunteering, PPI may help with building confidence, regaining skills, and learning new ones. These activities may also be a good way for a person to gage what they might be able to do and manage safely in a job.

Job creation – See link to Catherine Hale below.

- Career guidance
- Options to retrain.
- Support to complete studies.
- Coaching in work

We know that some people have successfully moved into new jobs and found supportive employers.

Red flags

In this section we alert the Committee to our serious concerns regarding the health and wellbeing of people with Long Covid and many people who are currently unable to work.

We know the numbers of people with Long Covid are rising and we signpost you to this important report: The economic impact of Long Covid: See here.

- ## Musculoskeletal (MSK) conditions existing and new onset

When we think of employment support for people with Long Covid we can't just see their Long Covid symptoms in isolation. We must also consider any comorbidities and pay close attention to potential risk factors associated with working e.g. ergonomics.

We question whether legislation e.g. workstation assessments are being carried out, or s gone a mis due to the pandemic.

We are not surprised to see this TUC report on MSK problems due to working from home https://www.tuc.org.uk/blogs/working-home-shouldnt-cost-us-our-health-heres-what-employers-should-do but we are disappointed that this should be well understood by employers in 2024.

Ceolta-Smith raised this matter in her oral evidence for Long Covid Support in Plan for Jobs and Employment Support in 2022 " *Bearing in mind that we have already heard about the ONS data on musculoskeletal problems, we do need to ensure that, if people are working at home, the onus is on employers to ensure that they are following legislation in terms of things that are provided*" Link here.

So, there is a need for healthcare, OH and vocational rehab practitioners to ensure they assess holistically and if they are not already to advise on such matters especially when someone is working from home. This may well increase the referrals for Access to Work provision in and we wonder if this provision has the capacity to meet any increases in demand.

Health and safety legislation for workstation assessment are of key importance and we must make clear that we are aware of people with Long Covid who work from their bed or sofa. It is important to note that autonomic dysfunction is extremely common in Long Covid and needs proper treating to improve daily function. In the vast majority of places in the UK, no one has access to any treatment for this and expertise is urgently needed. This includes POTS see here.

- **Government's policy proposals**

These are appearing at a rapid and alarming pace and are a cause for serious concern, for example with the proposed changes to the WCA and we responded to this consultation: See here. The proposals are especially concerning in terms of the focus on the PIP assessment determining fitness for work and role of work coaches. We do not see this as fit for purpose and to be dangerous in terms of the potential harm to people's health and wellbeing.

- Fit Note – these are essential if someone gets back to work and needs to take time off if their condition fluctuates or worsens for example, due to a reinfection. We worry about presenteeism too.

Other concerns are:

- SSP and inadequate or no safeguarding at the DWP/ Jobcentre all of which we know you have had a session and report on.
- Government's relentless 'minimisation of disabled peoples' needs including mental illness is of significant concern. We also raise questions about how many people who are already claiming benefits with a primary mental health condition may also now have a diagnosis or undiagnosed Long Covid.

- A lack of clarity over what employment support programmes will be made available to disabled people and people with health conditions when the work and health programme is due to close in the autumn.

In 2021 your response to the inquiry we responded to on Employment Support stated: “the *Department was asked to “out how it will tackle the long-term effects of the pandemic on the jobs market, disabled people, and particularly those who suffer from long Covid"* Yet we are not aware of anything specific for people with Long Covid and it is now 2024.

Furthermore, we know some people with Long Covid have asked their MPs about what employment support is available and just had a generic response.

- We have many questions about Work Well, for example regarding the possible use of social prescribers and who will be the work and health specialists. No health knowledge or a little knowledge can be dangerous when giving advice on work preparation and work for people with Long Covid.

We remain concerned about the future health and wellbeing of people with Long Covid who are experiencing significant financial hardship. We know people who are not eligible for benefits, or struggling to access these who are having to sell their home. See the joint report by TUC and Long Covid Support March 2023.There isn’t a safety net for all, and whole families are being impacted.

Good work is generally good for physical and mental health

We understand and know the value of good work. We all want to work, but we call on all stakeholders to be measured in the claims made about good work being generally good for our health when explicitly focused on people with Long Covid and some other conditions including ME. The highly cited research publication for this evidence claim is dated 2006. We know that the world of work has changed significantly since that time and the health and safety risks of contacting COVID 19 and reinfections which can worsen and disable people already ill. In addition, many workers are extremely pressured due to ongoing levels of sickness absence in the workplace, and there are high numbers of staff reporting burnout and mental ill-health.

We need research into treatments for Long Covid along with ME and to identify what supports pwLC to sustain work and to be as well as possible in all areas of their life. We call upon our government and the DWP to urgently grasp that for many people with Long Covid who are currently working including those on reduced hours and pay very often have no quality of life i.e. they must rest on their days off work and struggle to undertake their usual activities of daily living. And many people with Long Covid have no financial security while experiencing the threat of or worsening of ill health especially with the possibility of changes to PIP. Evidence shows financial stress can worsen health too. This situation is not fair, reasonable, moral, or ethical. We also have a growing rate of suicides as announced by Professor louis Appleby and financial stress which people with Long Covid are experiencing is known to be a triggering factor.

Furthermore, we signpost the Committee to all the recommendations made in the TUC and Long Covid Support report in March 2023.

Finally, pushing people with Long Covid into unsafe and unsupported work risks the worsening of their health and wellbeing as shown in a woman who returned to work and had to cover for her colleagues who were off sick in this recent news piece by BBC.: Tracy Evans, contracted severe Long Covid in January 2021 after 30 years as a care assistant. She told the BBC she has been unfit for work due to symptoms (...) severe fatigue & brain fog. … "she tried to go back to work last year. "I thought that would be ok because many of the tasks I was given I could be sat down and resting," she said. However, staffing shortages led her health to deteriorate further and left her "in bed for weeks". As a result, Mrs Evans was forced to give up the job she loved."

Key resources for stakeholders on supporting people with Long Covid into paid work.

Long Covid and Return to Work- What Works? A position paper from the Society of Occupational Medicine. August 2022:
https://www.som.org.uk/sites/som.org.uk/files/Long_COVID_and_Return_to_Work_What_Works.pdf

The Society of Occupational Medicine: Long Covid A manager's guide February 2024:

https://www.som.org.uk/sites/som.org.uk/files/SOM_Long_COVID_A_Manager%27s_Guide_Feb_2024.pdf

CIPD research – Working with Long Covid Research evidence to inform support Feb 2022:

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Current research:

We are aware of new NIHR funding opportunities focused on long term conditions and employment and a current study:

Can flexible job design improve employment outcomes for people with fluctuating disabilities? King's College London

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Case Studies A, B, C

These three case studies have been written by people with Long Covid (which is why the writing style varies across all three cases) and provided to Long Covid Support in confidence All identifiably details have been omitted.

Case study A - Job and hours maintained, no long-term sickness absence taken. Fully supportive employer and line manager.

BACKGROUND AND TIMELINE:

Worker in their sixties employed in a senior healthcare post in an NHS organisation. Prior to the onset of Covid infections, they had no known health conditions and was considered fit and well. Sickness absence was previously zero.
Mid 2020:

Developed what was considered to be Covid19, soon after attending a [work event]. There was no diagnostic test available at this time, but a subsequent infection in 2021 followed both a near exact pattern, and a confirmed diagnosis. This first episode was characterised by a five-day period of acute musculoskeletal pain and an intermittent headache with. retro-orbital pain, (pain behind the eye) approximately 6/10 on the numerical pain scale. After five days of total bed rest at home, they had a planned five-day Annual Leave period, after which they felt well enough to return to her whole time equivalent professional work life. Although they felt somewhat 'post-viral', characterised by an unusual degree of tiredness, there were no other noticeable symptoms or sequelae at this time.

Early 2021:
Had a second episode of Covid infection; this was diagnosed on a positive PCR (Polymerase chain reaction) test. The disease process was strikingly similar to the episode in mid 2020 however the recovery period was *markedly different*, characterised by the onset of new or differently presenting symptoms.

The new differences were:

1. The ***strength*** of the musculoskeletal pain was now entirely 8-10/10, with an increase in the number of occurrences, albeit fleeting in nature

2. A new and distressing symptom of breathlessness on minimal exertion, typically, climbing one flight of domestic stairs (13 stairs) resulted in a drop of oxygen saturation to approximately 90-92%

3. An increasing lexical difficulty in oral word -finding, similar to an expressive dysphasia. *Note, this did not apply to written word-finding which seemed unaffected*.

4. Simultaneously, there was a new and significant fatigue.

Work status: attendance at work remained full, on a WTE (1.0) contract.

Process of returning to work, there was no absence as the disease process was manageable with excellent work-support. No barriers to returning to work because of the solutions agreed below.

Solutions:

A full and comprehensive conversation was had between the person and their line manager. The person requested to stay in full time employment with specific 'work arounds' to enable and support this. These were agreed and reviewed monthly at formal 121 meetings to ensure their continuing efficacy and appropriate level of support or intervention.

Staying at work:

This was enabled by all of the following: working effectively, synergistically, and in partnership, to provide a real and beneficial solution, over a three-year period.

1. A fully engaged and supportive line manager
2. Agreement to work from home on an 'as required' basis with the parameters set by the person.
3. Agreements to fully flex work hours to support the individual, see 'wholly personalised workday' below
4. Formal offer to refer to internal Occupational Health
5. Offer to refer to internal Long Covid clinic resource, if wished to undertake this.
6. Ongoing informal psychological support from the team the individual worked within.

In short, everything possible was done to support and encourage the individual to remain in post.

Key recommendations from experience: 'mechanisms that worked'.

1. Working from home, when possible, meant that the environment was flexed to suit the individual i.e. no climbing of stairs, ability to rest in a quiet room between different 'business activities'
2. A wholly personalised work schedule. This was characterised as a 7.5-hour day delivered over extended hours.
3. Time to respond fully, professionally and appropriately. This involved identifying and implementing 'practical solutions' to understand what is required/helpful. For example, in managing spoken word finding difficulties.

Commentary:

This personalised approach to flexibility of work hours supported not just physical recovery, but also aided the deep psychological space of remaining an effective, fully contributing, team member. It was easy to implement, deeply pragmatic, and an appropriate mechanism. The person is an early riser with a preference to start work

earlier in the day, and as the majority of the workday hours had been completed by 13:00, the afternoon rest period ensured that the person was suitably refreshed and therefore able to attend and fully contribute to formal afternoon meetings.

Although this meant that the workday was 'longer', it successfully worked for both sides as the work standard and input /output was maintained, and the full engagement was spread over a time period that was realistic and not debilitating. Where, on occasions, a rest period coincided with the preferred attendance at a key meeting, a team member was allocated to attend this instead.

Case study B

More than two years on long term sickness absence and then returned to their employer in a new role with reduced hours to part time.

Lived Experience of return to work (RTW) with Long Covid

Process of RTW

It was clear that returning to my previous role was not going to happen, those usually in my position would take a sideways step from [one off site role to another onsite role]. This wasn't possible for me as both roles are safety critical. So, the decision was made between myself and HR to put me on the redeployment list, I had clear communication and was kept up to date.

The obstacles I potentially faced in returning to work were that I had no experience in an office environment, however I did have ok IT skills. The other thing is travel, I made it clear and the occupational health (OH), occupational therapist (OT) backed me up with this saying I couldn't travel far. It was agreed that I could work out of my [previous site location] and also from home.

Solutions

OH, have kept in contact but had really left my care in the hands of the specialised care of the Hospital/LC clinic. However, they did support me with counselling and cognitive behavioural therapy (CBT), when I reached out for my mental health which was a lot quicker than going down the NHS route.

I also felt that returning to work in a full-time capacity would be out of my reach, so along with the OT report and HR it was agreed that I would start my phased return doing 2 hours for 3 days a week and that I could slowly increase that over the initial 13 week phased return, with the option to increase that to 16 weeks. This happened without any issues, there was good communication with both HR and my new line manager.

[My organisation] has a policy so there's always someone to turn to if you need help and this has certainly worked for me. [several] years off sick and no threat to my

employment was a massive weight off my shoulders, I was a little worried as to what I could actually do but everything worked out ok.

After my phased finished successfully (I had goals to reach within my time) return I was invited to put in a Flexible Working Application on medical grounds where I could stipulate the number of hours I wanted to work. My line manager was in agreement that this adjustment would fit within my team and role.

Being listened to and not being gaslit was a huge benefit, I think the good working relationships I had before the pandemic really highlighted how I am today. They see the massive difference and it made them sit and take notice of what Covid can do. I remember seeing my old-[line] manager on a visit to work and later [they] confided in a friend of mine that [they were] shocked as to the toll covid had taken on me. [They] had seen the OH reports and was kept up to date with my progress, but actually seeing me in person was a shock, my friend then said [they] should've seen me weeks after hospital when a few steps would leave me breathless and exhausted.

Summary

It's been good to get back into work and have a structure to my week and I believe it's helped with my mental health. Working part time suits me as I get time to recoup before going back, but don't like the part time salary, but who knows what will happen in the future. I have felt that I have been listened too and I have been accommodated and I even have the platform where I have been able to tell my story within the company to bring awareness of Long Covid.

There has been small hiccups along the way, but those have quickly been addressed and have usually been out of any one's control, for example I had to wait for my chair to be delivered to home, but the delay was at the manufacturer.

My biggest recommendation was the long-phased return and the control I had over it, as long as it fit in with my role.

CASE C

Has had to exit work due to repeated COVID 19 reinfections previously worked full time in public sector.

I caught Covid at work early in 2020 and never recovered, I was 2 weeks into starting my new role in my dream job that I had worked so hard to get to. I then developed Long Covid and Postural Orthostatic Tachycardia (POTS) which has made performing the smallest daily activities extremely difficult. I tried to cling on to work for as long as I could, had multiple sickness episodes, bounced in and out for 4 years, reduced my hours, changed specialty and had reasonable adjustments put in place.

My life became about work, all of my energy would go into work, and I would spend my time not at work resting to recover and prepare to go to work again.
Unfortunately, I then caught covid again at work in 2022 and 2023 due to inadequate infection control policies.

My most recent reinfection has really destroyed any small progress I had made and even led to a pulmonary embolism despite already being on anticoagulation medication to prevent this.
This reinfection had such a profound impact on my health that I have had to stop working completely. I barely leave the house apart from for medical appointments.

It is extremely upsetting to have had to leave the job that I loved and worked hard for because of my health. I never imagined that I would be living with my parents at my age and not have any income. My future is very uncertain, and it is very scary. I am currently in the process of applying for benefits and am worried about this as I have heard such awful horror stories.
Most of my money at the moment goes towards private healthcare as there is no support for any of my conditions on the NHS.

It makes me angry to think that I am in this position because I went to work and was not protected. It has ruined my health, career, my social life and financial security. I have no support and no idea what the future holds for me.

There needs to be more recognition and support for those living with Long Covid, we have been forgotten about and this issue is only going to worsen as time goes by if Covid continues to be ignored.