



Long Covid and Employment Rights

Survey results August 2021

Background and Context



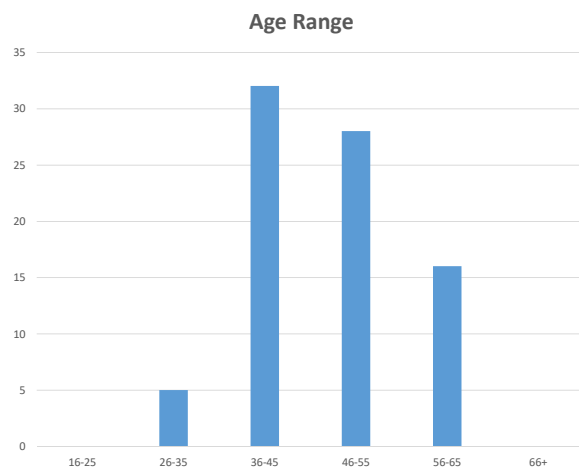
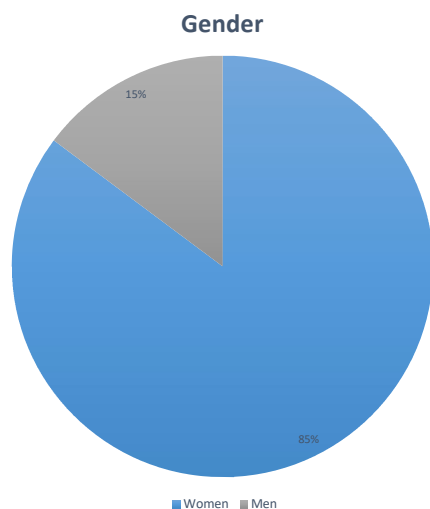
- Coronavirus (Covid-19) can cause symptoms for some people that can last weeks or months after the infection has gone. This is now widely known as Long Covid. It is having an impact on employers and employees as affected workers try to get back to work.
- GMLC's employment advice service has been receiving queries about what rights employees have at work if experiencing Long Covid.
- In April 2021, the Office for National statistics estimated that there were 1.1 million people in the UK with Long Covid. Of these, 122,000 healthcare workers were affected, 114,000 teachers and other education staff, and 31,000 social care personnel.

Our survey



- In July 2021, we started to speak to Long Covid support and campaign groups about their experiences and how they would like to see rights and policy change around Long Covid. We also followed up with clients who had called GMLC for advice.
- We opened a survey to ask about people's experiences of Covid-19, Long Covid, workplaces and benefits. Within one week, we received 81 responses from across the country.
- We pushed the survey via:
 - Facebook, on our profile and via a Long Covid support group;
 - Twitter, on our profile and via shares and the #LongCovidWork hashtag;
 - GMLC's newsletter.

Demographics of sample

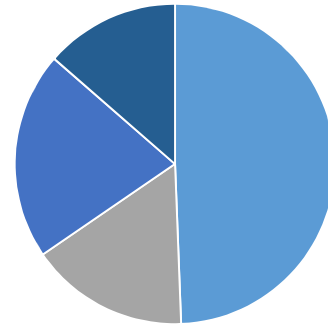


Catching Covid



- Not all participants gave a clear description of the environment they worked in at the time of catching Covid, but we estimate that around half of our participants were from healthcare settings, 46.9% working directly with patients.
- 49.4% of survey participants were certain they caught Covid at work or on the way to work, and a further 16% thought that they had *probably* caught it at work or on the way to work.
- Of those who thought they caught Covid at or on the way to work, 45.3% said there were no safety measures in their workplace at the time.

Where do you think you caught Covid?



- Yes, I am certain that I caught it at work or on the way to work
- Yes, I think I probably caught it at work or on the way to work
- I'm not sure where I caught it
- No, I think I caught it somewhere else

Safety measures at work



Many of those who said there were no safety measures at work mentioned that they caught Covid in the first wave, before official lockdown measures had begun.

"No one was aware of needing to wear masks, social distance or avoidance of using recycled air conditioning or reducing numbers who work in small area." - Clinical pharmacist at a hospital

"I caught Covid towards end of March 2020. I work at the university and lots of students returned to university in March 2020 from placements at a time when COVID safety measures were not in place." - Lecturer at a university

"I caught it in work definitely. The unit I worked in housed 3 prisoners with Covid. There was no PPE for me and no measures in place except hand gel at the entrance." - Prison administrator

Safety measures at work (2)



Others raised issues with their employers' handling of Covid at work.

"At the time I caught Covid (February 2020) my workplace did not have any Covid safety measures in place. I had to present at an international conference in London organised by my employer during the first wave of the pandemic when all other events in our field were being cancelled. My employer chose otherwise. In retrospect it would have been sensible not to go ahead with the event or to hold it online." – Worker in B2B services

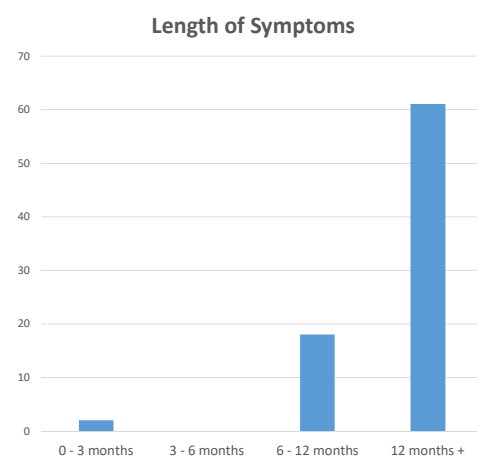
"[D]espite national NHS guidance that I should be working at home as I was in the high-risk group for Covid-19 chronic asthma, my manager did not tell me to do this. [...] I did two days of clinical work in a hospital (where I later found out there was Covid outbreak) when I should not have been working due to my increased risk factors and should have been working from home." – NHS Doctor

"As the service I was working for is an advice portal for Covid-19, they should have been more pro-active in putting safety measures in place at the workplace." – NHS 111 Call Handler

The duration of Long Covid symptoms



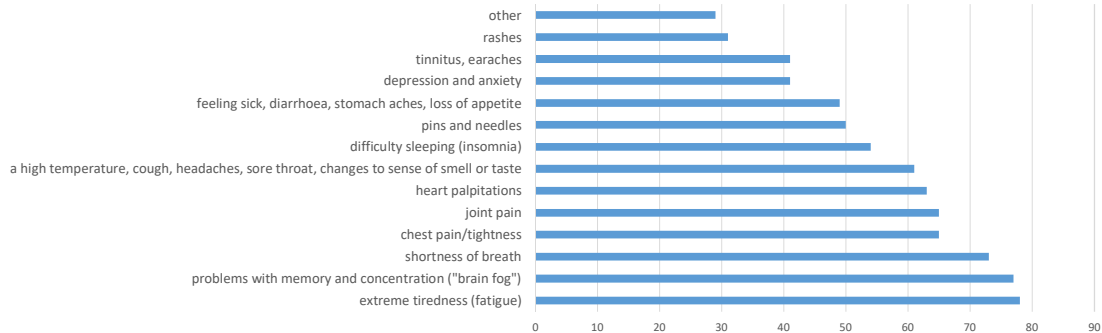
- All of our 81 participants said they were still experiencing symptoms of Covid now.
- 75.3% of our participants had been experiencing symptoms of Long Covid for more than 12 months.
- 97.5% of our participants had been experiencing Long Covid for 6 months or more.



Symptoms of Long Covid



What symptoms of Long Covid are you experiencing?



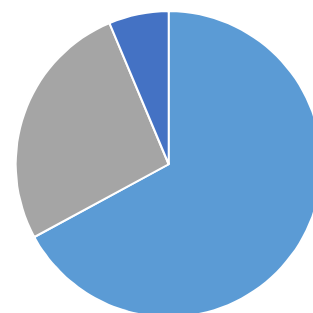
The most common symptoms were fatigue, "brain fog" and shortness of breath. More than half of the participants said they were now experiencing depression and anxiety as a result of Long Covid.

Long Covid and your ability to work



- 97.5% of our participants said that Covid has affected their ability to work – 79 of the 81 people who responded to our survey.
- Of those who said Long Covid had affected their ability to work, 67% said that they could not manage a day of work due to their symptoms.

Do your symptoms of Long Covid affect your ability to work?



- I could not manage a day of work
- I could manage a couple of days a week but it does affect my work
- It flares up once in a while and causes difficulties with working

How did Covid affect your work?



Many of our participants gave long answers to how their working patterns had to change as a result of Long Covid. One participant mentioned that their life had been “perpetually changed” by Covid, which reflected the tone of many of the other answers too.

Seven participants mentioned how “fatigue” or “tiredness” made travelling to work difficult, or made it difficult to get through the day at work. One participant described feeling “less reliable” as a result of their symptoms, and another described feeling that they worked slower, making it hard to meet workplace expectations. Inability to concentrate came up in many answers, with explanations of how this affected specific job roles across sectors. Others mentioned the impacts of symptoms such as chest pain and difficulty breathing, which prevented them from doing things like climbing stairs or getting out of bed, leaving them unable to work.

Many mentioned the “pressure” and “stress” of being expected to get better quickly by their employer, and fear of being laid off for no longer being able to achieve at work. One person said they felt “worthless” and another mentioned guilt about “no longer being able to contribute meaningfully”.

Covid effects on work visualised



How employers handled Long Covid



We asked how employers had treated people after they contracted Covid. From the 54 participants who provided a written answer, we extrapolated that 72.2% of those people had, overall, been supported by their employer or given reasonable adjustments to their working lives to help them cope with their symptoms. Some described their employers as “supportive” and “sympathetic”.

However, 27.8% of participants who answered this question told us that they had real difficulty getting support at work, and four participants had been laid off as a result of their symptoms.

Participants commented that it was “difficult” to get support, or that they were put through standard absence procedures that did not take into account the persistence of the symptoms. Several commented that they had been “disbelieved” or “belittled”. One participant said their experience had been “terribly negative”.

How employers handled Long Covid (2)



“[N]o one understands the seriousness of my diagnosis. Although [I have been] allowed to return to work on a phased return, no adaptations that were requested have been done. I feel alone, a nuisance and constantly expected to do more than my reduced hours per day.” - Clinical pharmacist at a hospital

*“They are trying everything to get me back to work by hook or by crook, and don't seem to care that I am sick & suffering with little or no help in sight. At one point they even tried to make out that my Long Covid symptoms e.g. joint pain etc. were not related to Covid and tried to dismiss me using sickness procedures.”
- Office worker*

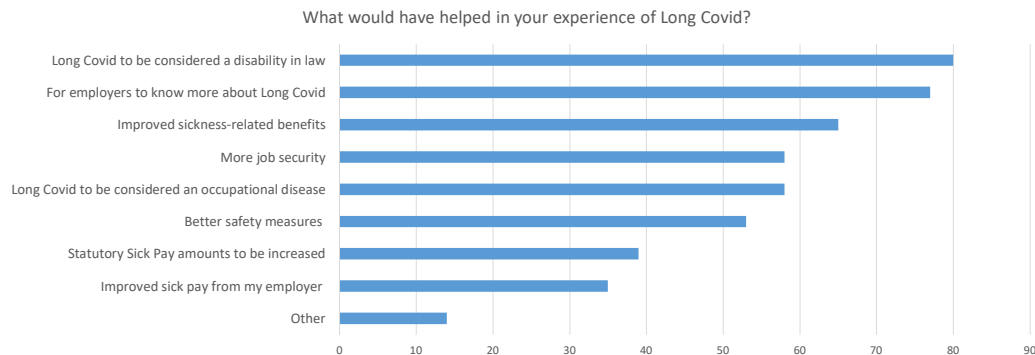
“They doubted me [...] treated it as normal sickness and reduced my wages. [This] caused me extra stress on top of my Long Covid. [They] refused to take any responsibility that I might have caught it within the workplace.” - Nurse at a hospice

“Work put me in a position of having to fight my corner for 6 months. Instead of supporting me to recover, and wanting to understand the impact of symptoms, I had to fight for my job and health at every meeting, until they sacked me.” - Former worker in financial services

*“I was rapidly processed through the sickness absence procedure and told to “get some fresh air”. I was invited to the first formal meeting by text, with less than a week's notice and without being informed I could have a union rep present. I had to fight for months for my illness to be recognised as Covid-related.”
- NHS worker (office-based)*

“[It] required Unison [trade union] involvement to protect my job.” - NHS therapist

What do Long Covid sufferers want?



98.8% of our participants wanted to see Long Covid to be considered a disability in law. 95.1% wanted employers to know more about Long Covid so they realise it is a serious illness and take into account guidance on how to treat employees.

Long Covid and the benefits system



Some of those who were no longer working, or off sick, discussed their interactions with the benefit system. Most who had applied for benefits raised the issue of the complexity and difficulty of the process, and many were annoyed with the outcome.

"I've applied for PIP but been turned down twice and going to tribunal. The assessor twisted what I said and blatantly lied on my assessment. The whole benefits system stinks. I didn't ask to end up like this and there are thousands like me." – Restaurant worker

"I have made a PIP claim but do not know the outcome. The form was difficult to complete in my current health." – Probation office team leader

"I was not able to claim new style ESA as my income was over the threshold. [I] still struggled financially." – Teacher in a school

"The benefits system needs to recognise Long Covid and its many symptoms and make the process easier and quicker. I need help now, not in a year after I've lost my job." - Nurse at a hospice

Limitations of our data



- Our survey was only open for one week, and generally reached participants via social media. This will have limited who saw it, and probably meant that those most engaged with the issues already would have been more likely to fill it out. This may be a particularly badly affected contingent of Long Covid sufferers.
- The survey was made up of 23 questions, many of which gave the opportunity for the participant to give free-text answers. This may have led to our sample disproportionately representing those most comfortable with writing and with more time to write answers. This may be correlated with other factors such as their level of education or income, and this may in turn affect their answers, such as their priorities in relation to Long Covid.
- Our sample is small and should not be taken as representative of all those experiencing Long Covid.

General conclusions from our survey



- The survey demonstrated the seriousness of Long Covid and the devastating effect that it can have on people's working lives, especially on their ability to manage work.
- The survey highlighted the dangers of not having safety measures in place in the workplace, not just in terms of transmission of Covid itself but of the long-term effects of Long Covid on employees' ability to work. The number of participants who had experienced symptoms for over 12 months demonstrated that, for many sufferers, Long Covid could easily fit the definitions of a disability in law, since the requirements for this are that it must have lasted or be likely to last over 12 months.
- The survey's results highlighted difficulties with the benefits system that are already well documented, such as its delays, difficulty proving illness to the PIP assessment team, and the liveability of current benefits rates. These now affect large numbers of people who have contracted Long Covid and have turned to the benefits system for financial support.

Our recommendations



- The data suggested it is a priority Long Covid to be determined a 'disability' for the purposes of protecting employees against discrimination on the basis of their experience of Long Covid. This seems particularly pertinent given so many appear to have caught the virus at work, while on the 'front lines' of the Covid-19 pandemic.
- We recommend that employers seek out guidance and train all management staff to ensure consistency in the seriousness with which Long Covid is taken. Employers should take a supportive approach towards employees, in line with guidance such as Acas' here: [acas.org.uk/long-covid](https://www.acas.org.uk/long-covid)
- We recommend that workplaces continue to implement health and safety measures at work to ensure Covid does not continue to be spread in workplaces, especially healthcare settings. Adequate health and safety provision is a legal requirement.
- We suggest that benefits assessors are provided with detailed guidance around Long Covid to ensure that sufferers can obtain an income during periods when they are unable to work. This survey has shown, alongside many other pieces of research, that the system treats people facing ill health in a punitive and demanding way, which we consider to be unfair.
- We recommend a raise in Statutory Sick Pay and other sickness-related benefits for all claimants, and a less punitive benefits system that leaves people able to access the support they need without unnecessary barriers.
- We recommend that all employees join a trade union if they are not currently in one to enable effective negotiation and protection against poor health and safety practices, discrimination and redundancy.