



Long Covid SOS

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# Employers must provide better support to workers with long covid

People with long covid need to be believed, trusted, and offered flexible workplace adaptations by employers, writes S Thompson

S Thompson *advocate*

A recent report by TUC and Long Covid Support highlights the challenges facing people with long covid who want to remain in the workforce.<sup>1</sup> The survey of around 3000 people with long covid in the UK found that one in seven (14%) had lost their job because of reasons related to their condition. Two thirds of respondents (66%) reported experiencing unfair treatment at work because of their illness, including bullying or harassment, the threat of disciplinary action, or being questioned about whether they have long covid.

That so many people with long covid have had such poor experiences reflects wider societal problems in how we treat people with a disability or ill health—particularly people who have an invisible illness. Many people living through long covid have had their symptoms trivialised and the adaptations they need as an employee dismissed. As the report states, “Previous research on energy limiting impairments demonstrates that there is much scepticism about the existence and extent of fatigue and a view that it is not a ‘real disability,’ creating additional barriers for people who need support from their employers.” One way to challenge prejudice and validate these conditions would be to identify them as a disability under the Equality Act 2010.

A broken bone is relatively simple to see and manage; we know that the bone needs to be brought into alignment and given time to heal, and people can be given a “usual” timeframe for this recovery process. Yet we still have a limited understanding of the prognosis for long covid. The trajectory of people’s symptoms seems to be individual and variable, meaning that the standard six week phased return to work is not appropriate for the majority of long covid survivors. A successful return to employment needs to be based on employers trusting the validity of their employee’s symptoms and what they’re reporting on a daily basis. The TUC report shows that 90% of those surveyed had fluctuating symptoms, meaning that support to return to and stay in work needs to be flexible and not linear.

As someone with long covid, I know that there is a tendency to doubt yourself when you have this condition. Many of us do not want to feel we have given in to this illness that has eaten away at life as we knew it, and it can be tempting to try to push through your symptoms, often causing them to worsen. The TUC report shows that many people try to do exactly this, with one in 10 people with long covid not telling their employers about their condition. About a third of those people said that this was because they didn’t think anything would change and another third worried that their employer would

view their symptoms negatively. These fears are also relatable, but come at a cost.

Long covid is a condition that is hard to understand even for the person experiencing it. I can often pace and plan for certain symptoms after specific activities, but at other times they worsen for no identifiable reason. If I struggle to explain my symptoms to myself, it must be harder for someone who doesn’t have long covid to truly understand. But do they need to? Employers don’t need to have experienced long covid symptoms to trust an employee’s account of them and make changes to accommodate them. Yet half of those responding to the survey did not receive the adaptations they needed at work.

## A financial and emotional blow

Those in the health service with long covid have experienced a similar job lottery. A recent Panorama investigation revealed how many NHS staff have struggled to return to work and haven’t been supported by their employers.<sup>2</sup>

I was heartbroken, angry, distraught, disappointed—a mass of emotions—when I was told there were no adaptations available to me so that I could carry on working in the NHS. Unfortunately, in my case I have had to accept that I was not and am not well enough to work. The occupational health doctors who assessed me could see that I struggled to hold a conversation. I need to break everything, including writing this, into small pieces in order to pace myself and manage. But my situation is extreme. I see colleagues across the country who could work now if they were supported with adaptations and flexibility, but they are denied them, condemned to the same fate as me. With full support and understanding, they could still be a valuable part of the workforce.

There are shining examples of success among people who’ve returned to work with long covid—where employees have been offered slow, flexible phased returns that take months or years, and where the goal is to balance work, life, and illness. In these cases, employees are at the centre of conversations about returning to work and are asked what they need and can honestly manage—not on their best day, but on their worst. Strong collaboration is needed between employee, occupational health, HR, and the employer to make this happen. Any relapses in an employee’s symptoms should be met with swift action to reduce their hours and responsibilities, in turn reducing the length and impact of the relapse.

Finding yourself unexpectedly limited physically and/or cognitively because of long covid can be devastating. Yet being unable to work—either because

you can't or your employer refuses to make the adjustments that would allow you to—is a further blow, both financially and emotionally. The key to supporting this group of people is shunning stigma and embracing an open culture of understanding and trust.

Many people with long covid are frontline health and other key workers who worked through the worst of the covid-19 pandemic. That they should now be disbelieved or dismissed, instead of supported, is a great injustice. Recognising that each person with long covid is unique, believing them, and personalising adaptations to their symptoms can make it possible, practical, rewarding, and fulfilling for people with long covid to work—it just needs the support of employers to make it happen.

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- 1 TUC and Long Covid Support. Workers' experience of Long Covid. 27 Mar 2023. <https://www.tuc.org.uk/research-analysis/reports/workers-experience-long-covid>
- 2 Panorama. Forgotten Heroes of the Covid Front Line. BBC. 30 Jan 2023. <https://www.bbc.co.uk/iplayer/episode/m001c2dg/panorama-forgotten-heroes-of-the-covid-front-line>