

ACKNOWLEDGEMENTS

Our thanks go to all the many individuals living in Scotland with Long Covid who have openly and honestly shared their experiences of how Long Covid has impacted their employment.

As volunteers at Long Covid Scotland, we are not researchers but have some limited experience.

Over the last two years, Long Covid Scotland has worked hard to advocate for lived experience to be meaningful and integral to all decisions and provisions for Long Covid, given that those living with Long Covid for the past two years are amongst the best experts.

<u>Author</u>

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My thanks go to Alison Love for assisting in designing the questionnaire and to Jane Ormerod, Chair of Long Covid Scotland, for keeping me right and proofreading.

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EXECUTIVE SUMMARY

The legacy of watching the distressing scenes in Wuhan, China, at the start of the Covid-19 pandemic could not have been foreseen. The legacy we are left with is Long Covid.

Those scenes of distress and anguishing scenarios did materialize in Scotland and have not only left trauma and the unimaginable loss of life but a devasting loss of ability 'to live' a pre-pandemic life for those adults and children who have been left with Long Covid.

The keyworkers who served on the frontline are now facing the greatest burden of Long Covid; we know that females of prime working age are the largest group affected, with some of the professions most affected being medical, education, childcare, and social care.

Long Covid has rendered people unable to work, many since the first wave of Covid-19 in early 2020, and the impact of not working for over two years is not only deeply felt by individuals but within the workforce. The symptoms of Long Covid make a return to work challenging at best to impossible without appropriate understanding from employers providing satisfactory support. Shocking numbers of people have reported disability discrimination arising from a lack of reasonable adjustments in accordance with the Equality Act 2010.

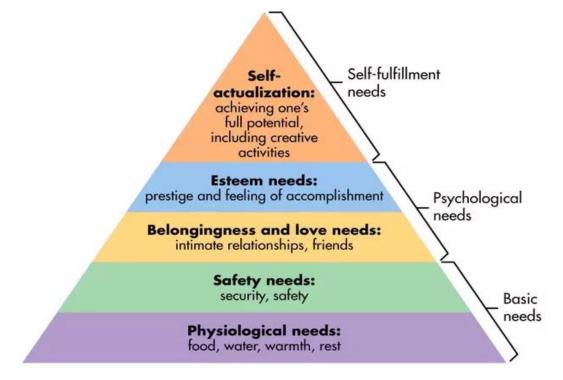
Occupational Health has been variable in its provisions and support owing to the imbalance given that it is commissioned by employers. This imbalance of power between employee and employer resonates loudly within the summation of the Fair Work Convention values. Workers with Long Covid feel undervalued, lack job security, and respect, and do not feel listened to. Self-employed people have been left to flounder and abandon ship causing devastation.

What people have made clear is that current policies and practices for long-term absence do not fit the 'relapsing and remitting' nature of Long Covid; it is something on a massive scale, never seen before. As an invisible disability subject to disbelief and gaslighting, it is time that managers and employers embrace that their employees still exist, and still have skills and knowledge but may require significant adjustments. The years of dedication, training, and experience must not be lost when workplace adjustments can be made. Alongside this, the manner in which Long Covid has been sprung upon us means that at a time of great strain within NHS services, treatment is not forthcoming nor are the answers for resolution of all the symptoms or the problems coupled with being unable to work.

BACKGROUND

The rapid spread of the Covid-19 pandemic led to the unannounced stealthy emergence of Long Covid. Through social media support groups and discussions with our members, concerns surrounding employment due to Long Covid, have continued to be frequent. Becoming disabled in a short period to the point where a return to prior employment has been unattainable usually results in financial detriment and can limit career prospects. Not only this, but a sharp decline in income creates uncertainty surrounding the affordability of existing housing and within the current cost of living crisis, the loss of a steady income in tandem with a harsh decline in health paves the way for mental health to spiral out of control in addition to the many other Long Covid symptoms.

Maslow's Hierarchy of Needs depicted below illustrates why constant salary during illness is so important. The rising costs of food, heating/energy and time to rest all have a price and contribute to feeling safe and secure. Governments and other stakeholders need to focus on a joined-up approach to ensure that whilst the world of biomedical science unearths a treatment that can be rolled out, that people with Long Covid receive other sources of support.



One of the most important aspects of this report is the quotations from people living with Long Covid. They are the voice of lived experience, the boots on the ground and they tell it as it is without embellishment. Lived experience is essential alongside the data we are providing to be able to set the scene and look to where improvements need to be made. The first step is listening to the voices of people with Long Covid and their real experiences.

As a new disease, Long Covid has prevented people from returning to work or their prior levels of health, and whilst much rhetoric surrounds what treatment or care pathways are needed, along with the hopeful discovery of what causes or prolongs Long Covid, meantime people need to survive financially. By focusing on employment, we wanted to see how Long Covid has impacted people's ability to work, earn, to provide for their families and what the provisions are for people in terms of absence and sick pay.

We hope by sharing this report that all stakeholders involved with Long Covid will use the information to improve existing provisions and continue to provide supportive outcomes for all people with Long Covid as part of a well-coordinated plan. By looking at what seems to be currently working well, where inconsistencies are and by highlighting what can be improved, we hope that processes and policies will evolve to take account of any inequalities and inequity.

In June 2021, the TUC published <u>Workers' experiences of long Covid</u> and in February 2022 the CIPD published <u>Working with long COVID: Research evidence to</u> <u>inform support</u>. This report by Long Covid Scotland is the first looking purely at the impact of Long Covid on employment within Scotland.

There are existing expectations laid out by the Equality Act 2010, the Scottish Government <u>Coronavirus (COVID-19): fair work statement</u>, <u>A Fairer Scotland for</u> <u>Disabled People: Employment Action Plan</u> and <u>The Fair Work Convention</u>. This survey highlights areas where these policies have been or have not been implemented.

"Disabled people's lived experience is central to shaping the action we take, and we will continue to work in partnership with disabled people and their organisations, ensuring their voices are at the heart of our work."

from <u>A Fairer Scotland for Disabled People: Employment Action Plan</u> (page 5).

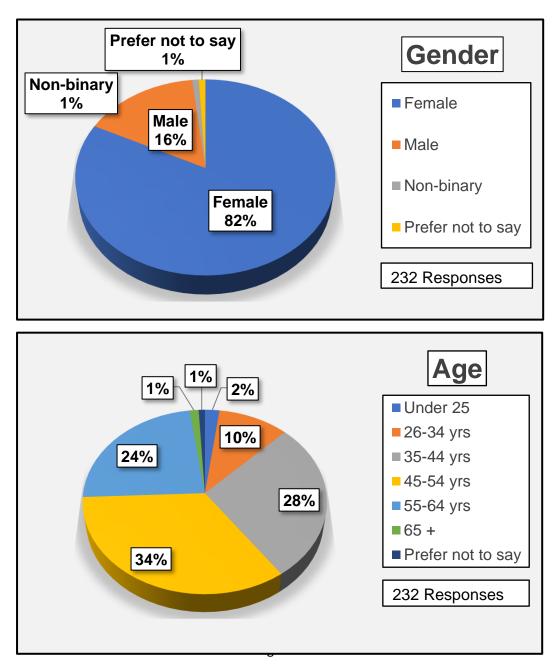
METHODOLOGY

The survey was created as a Google form which was shared via social media and limited to residents of Scotland. Participants were not offered any incentives to complete the survey. Any responses from residents outside of Scotland along with any duplicate responses were removed to give a total of 232 qualitative responses. The results have been analyzed and reported on by Long Covid Scotland.

RESULTS

Demographics

There were 232 people living with Long Covid in Scotland that responded to the survey. Overwhelmingly, 82% of people identify as female indicating that Long Covid disproportionately affects women. It affects those of prime working-age with the largest group affected being those aged 45-54 years old. At this age, many people will have made career progressions, possibly worked many years within an industry or for a specific employer, and with regards to women, they may have had to work all the harder for career progression if they had taken an earlier career break or reduced hours to raise a family following maternity leave. As it is, women often face incommensurate earnings compared to men and are more likely to be single parents.



Employment status

When asked if they were employed 85% of people stated they were, however, 15% of people had lost their job to either Long Covid or Covid-19. According to the <u>ONS</u>, Scotland's rate of unemployment has been 3.5%-3.8% during the surveyed period yet the rate of unemployment for people with Long Covid has been almost <u>four</u> times higher than this. Given that the ONS report states that in the UK, the greatest employment gap for disabled workers is from 45 years upwards, the prime target age for Long Covid, this is truly concerning for the aging workforce now disabled by Long Covid.

Across all age groups, the employment rate was lower for disabled than non-disabled people, with the greatest employment gaps seen for those aged between 45 to 49 years, 50 to 54 years, and 55 to 59 years. The employment gap for disabled people aged 45 to 49 years was 32.9 percentage points, for those aged 50 to 54 years it was 34.5 percentage points, and for those aged 55 to 59 years it was 34.7 percentage points.

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/d isability/articles/outcomesfordisabledpeopleintheuk/2021

To delve more deeply into employment status, we asked people if they had resigned, taken early retirement or requested a career break due to Long Covid. The 15% of unemployed people include those who resigned, were medically dismissed, retired, or ceased self-employment with an additional 3% taking a career break or leaving the workforce temporarily. A further 6% were redeployed or worked reduced hours.

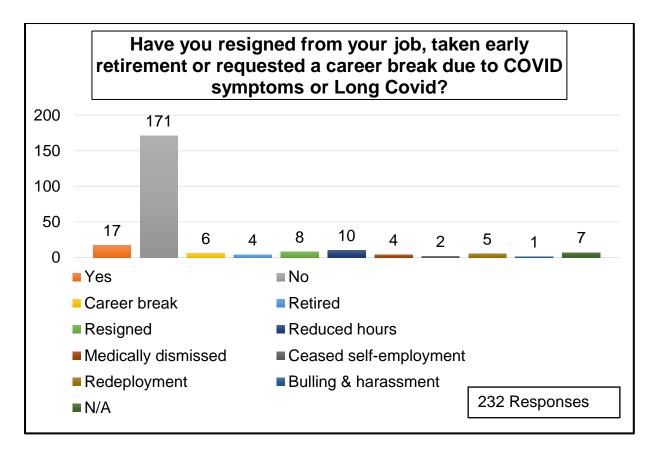
"It is a very uncertain time. If I am off too long, then I know as I have heard from lots of teachers (covid support group) that have faced dismissal or resigned. Sickness policy also states this could happen."

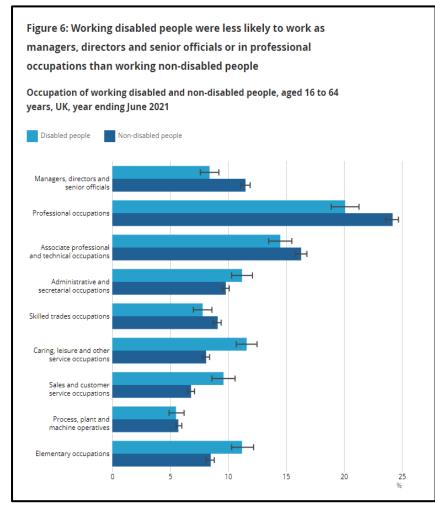
"My workload has actually been increased since my return to work, I believe, to encourage me to resign. Management hasn't supported me, and I feel that I'm not valuable anymore as I dared to say I was struggling with my workload."

"At the job I had when I first came down with Long Covid I was put through Aberdeen City Council's standard procedure. Rather than deal with the final stages, I felt it was easier to resign."

"Declared medically unfit. If I resigned, I'd lose housing benefit for 26 weeks, which would leave me homeless."

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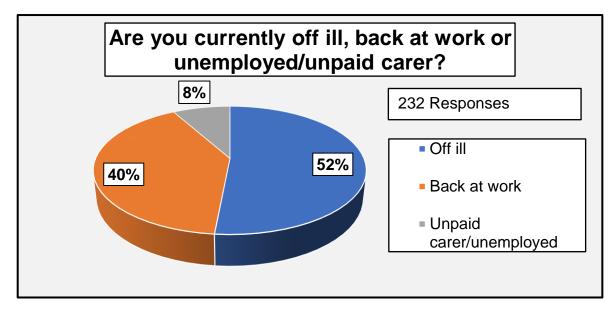


According to the ONS (Figure 6), working disabled people were less likely to work as managers, directors and senior officials or in professional occupations than working non-disabled people (June 2021).

Given that the employment rates for disabled workers aged 45 and older drops significantly, professions that worked the frontline during the pandemic, were hardest hit by Long Covid (medical, health, and education stand to lose their most experienced staff causing a deficit to the workforce).

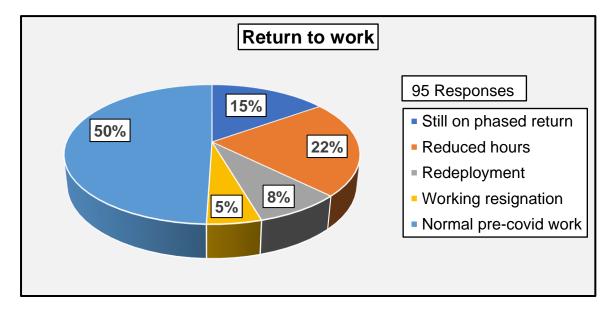
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In looking at whether people are still absent or whether they have returned to work the numbers are very split but with a clear majority of 52% still off sick. It will be very important to ensure that these employees are well supported to be able to bridge a smooth return to employment to avoid the loss of experienced staff. It is in the interest of both employer and employee that this symbiotic support network develops and becomes the norm. The <u>CIPD report on Long Covid</u> is an essential resource.



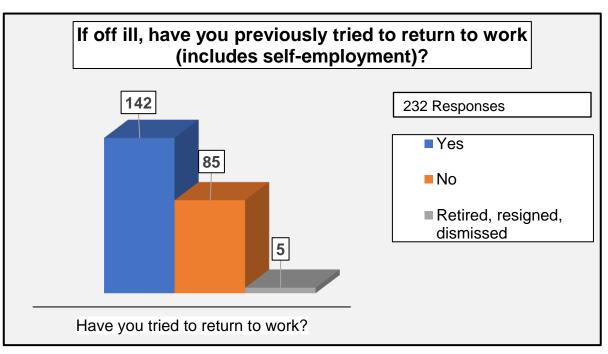
Return to work

Only 20% of people have been able to sustain some type of return to work; 2% were redeployed, 12% were on reduced hours, 2% were homeworking and 2% made a career change. Only 3% of people have returned to their pre-Covid-19/Long Covid working pattern meaning that 97% of people have been unable to sustain a return to work in the same fashion as pre-Covid despite 38% attempting to return leaving 62% that have not been able to return to work at all.

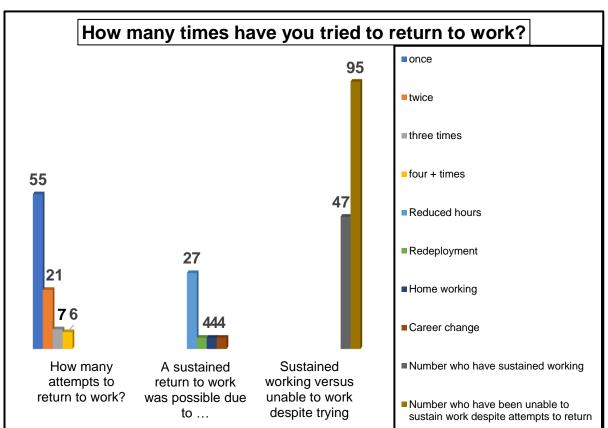


Despite 61% of people having attempted to return to their employment, as previously indicated only 3% are back to pre-Covid levels of work and a further 17% have sustained employment, mainly through a reduction in hours which has impacted their earnings.

"Disabled people work in every sector of our economy, but are more likely to work fewer hours and earn less than non-disabled people."

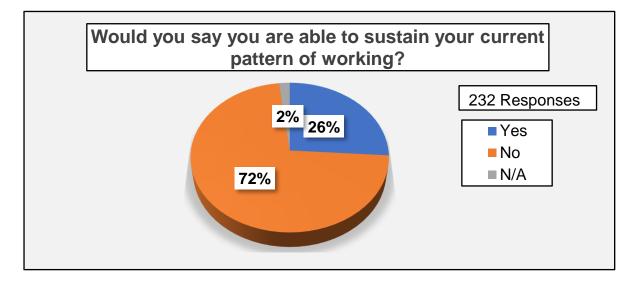


A Fairer Scotland for Disabled People: Employment Action Plan, page 15



Return to work experiences

The main barrier preventing a successful return to work was a symptom relapse with fatigue, exhaustion, and general worsening of symptoms being most highly cited. Some people had inpatient care as a result of exacerbations following a return to work. Of the people who sustained working, this was only possible due to working amendments such as reduced hours, working from home, or a change of job/career. Some participants said that the drive or commute to work negatively impacted their symptoms and several people said that lack of support from their employer contributed to their failure to sustain a working pattern.



Being unable to work and contending with a chronic illness impacted mental health. Pushing through symptoms to attempt a return to work before being truly able to, has adverse effects on physical and mental health. The vast majority of those working stated that they had no quality of life as time outside of work was spent resting or sleeping. Being back at work has generally caused worsening symptoms, and aggravated fatigue, leading to exhaustion.

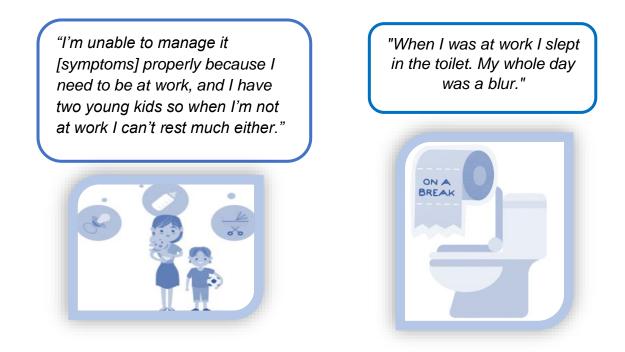
We know from the lived experience of over two years and from solidarity in learning from people with Myalgic Encephalomyelitis (M.E.) that the more a person relapses or 'crashes' the greater the price to one's overall health and ability to bounce back to a previous baseline.



"Each return [to work] led to a massive "crash" making me bedbound once more"

"I work and sleep. That's it, can't do anything else."

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"I am unable to undertake my previous clinical role due to ongoing breathlessness and fatigue. I am now only able to work on my hospital ward in the morning and I am desk based in the afternoons. I have been steadily trying to increase my hours for the past 2 years with difficulty."

"Can worsen fatigue, rely on weekends (when I'm off) to recover. Aches and pains worse after a week at work. A lot of walking around hospital wards and to and from the car (as denied a parking permit) can worsen symptoms."



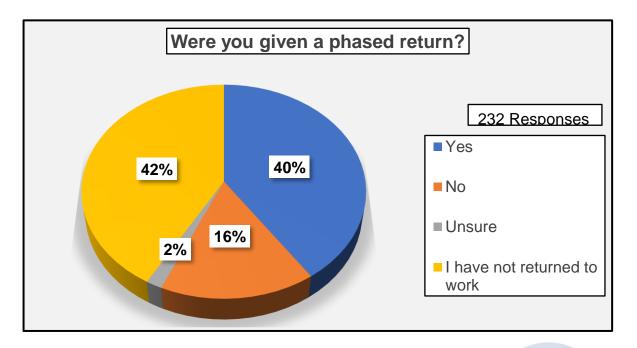
"I am constantly crashing after working, and it makes my symptoms a lot worse. I have to accept that I know I will crash at the end of each day and week or work, and take days to recover before I work again."

"No energy for anything else other than work, have to work to have money"



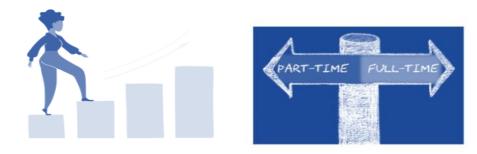
The structure of a return to work and its impact

Of the people who have attempted a return to work, around two-thirds were given a phased return. The length of the phased return was very variable. It was the longer phased returns of at least twelve weeks or indeed over months that were the most successful. A phased return in tandem with other measures worked most successfully. Those who tried to return to full-time roles within a standard four-week phased return were those who failed to sustain a return. To pad out the phased return period 19% of people used accrued annual leave.



"Reduced hours...reduced days, amended duties...4 weeks phased return....didn't manage this had 2 relapses."

"November 2021 - Started at 25% of my hours and flexible working. Managed only 2 days one week and 1 half-day next week before had to return to sick. I started a new job in March 2022 which is apparently less stress and more flexible with ability to work from home."



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Phased returns, when provided, varied enormously and ranged from a basic fourweek plan, sometimes to six or eight weeks with the lengthier thus more successful phased returns being over months, often up to six months. The length of a phased return is extremely important as Long Covid is a relapsing and remitting condition with fluctuating symptoms.

ACAS recommend a mutual agreement on how long the phased return will be for but in practice, this is not happening to the detriment of employees.

"The employer or their HR manager and the employee should agree on a plan for how long this will be for." <u>ACAS</u>

"I am worried about what happens when I reach the end of my phased period as the manager is already talking about areas of work I will 'have' to pick up as 'everyone in the team has to take on areas of work'. I think they have lost patience with my needs." "I feel that they think once my phased period is done that's me recovered and well enough to be back full time doing a full job - which I'm sure I won't be able to manage (short of a miracle cure appearing!)"



"My council's phased return policy is a one size fits all and doesn't seem to be able to be flexible and meet differing needs."

"First attempt: phased return over 4 weeks. No real structure in place. Began at the normal starting time of 7 am and was told to work until I had to stop due to fatigue etc. I usually managed until 4-5pm. After 4 weeks this was no longer possible, and I could not continue. No amended duties at all."

"I tried around half a dozen times as my former employer kept pressuring me to return. I was physically and emotionally unable to perform my duties as a butcher." Within a phased return period there is also great scope to ease employees back to work through other modifications such as a temporary reduction in hours, amendments to duties, home working where possible, accessible parking, more or extended breaks, and the acquisition of equipment to assist or re-training if required. Here are the voices of lived experience:

"There's been no attempt to support me or offer amended duties. This is after 20 years of exemplary teaching service."



"Refused disabled parking, breaks as required and reduced duties. No reason given from head teacher 'I can't be expected to accommodate these things'."

"I do not feel respected. Their attitude to my amended duties proves that."



"I was supposed to be on amended duties, but that did not last long."

"I was self-employed and had zero employment rights."



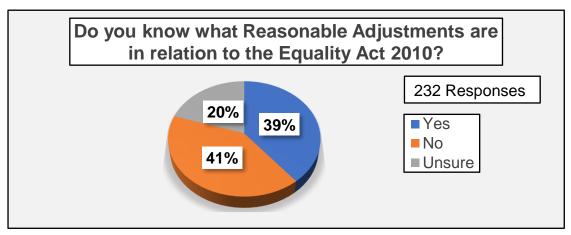
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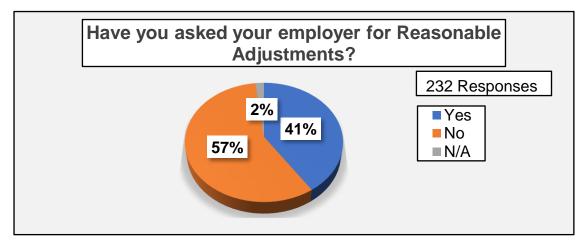
Reasonable Adjustments in relation to the Equality Act 2010

The symptomatology of Long Covid can be variable in its presentation and duration although what is known is that it can cause a staggering range of symptoms culminating in rather sudden disability. The issues with this are:

- Long Covid is not always immediately diagnosed, especially without the presence of earlier testing during the acute stage. This can lead to disbelief and gaslighting from employers and colleagues.
- When sudden disability strikes, along with it comes many stages of grief and uncertainty, so it takes time to realize the label 'disabled' may apply, to assimilate how this will continue to impact day-to-day life and that of an employee.
- It is very challenging and daunting for newly disabled people with limited energy levels to navigate resources and policies.

What has become clear is that Long Covid and its symptoms fit within the description of 'disability' under the Equality Act 2010 and that reasonable adjustments should be made where possible to support workers returning to employment. Therefore, with many newly disabled people, it is appropriate that only two-fifths of people know about reasonable adjustments.





For the smaller proportion of people who provided further details and have attempted or sustained a return to work, a big key to success has been a reduction in hours which unfortunately comes with a reduction in salary. Amended duties have helped in some cases and the inclusion of extra regular breaks has been very helpful.

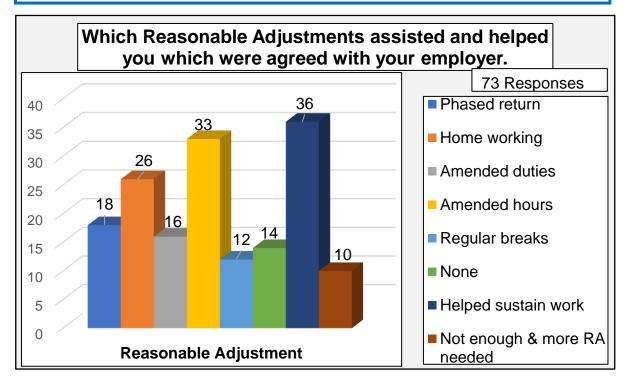
Working from home has been favourable in being able to pace symptom management and regulate workload although it should be noted that frontline workers with public-facing roles who were at the greatest risk working throughout the pandemic are met with greater challenges in attempting to secure home working as a reasonable adjustment given the physical, active nature of the normal role.

Despite the positive angle that a small proportion of people with Long Covid are reentering the workforce, most people have reported a sharp decline in quality of life brought about by a deterioration in symptoms, most notably fatigue. Failed phased returns and continued absence along with inflexible situations with employers caused 10% of these 73 people to become unemployed.

"Measuring impact and Next Steps To achieve our ambition of halving the employment rate gap in the next 20 years, the employment rate of disabled people will need to increase by at least 1 percentage point every year. We will review progress annually and set the following interim goals: (page 10)

• By 2023 we want to increase the employment rate of disabled people to 50%;

By 2030, we aim to achieve an employment rate of disabled people of 60%. A Fairer Scotland for Disabled People: Employment Action Plan (page 10)

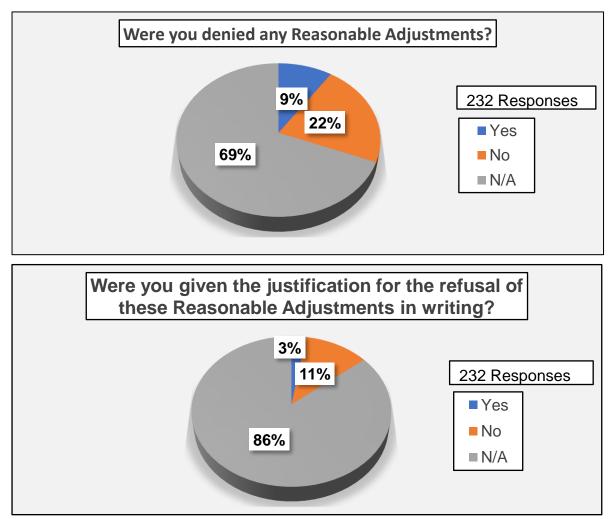


Out of 73 people who provided further details, 22 (30%) were refused reasonable adjustments overall and many others had specific requests refused. Here are the most common requests which were refused:

- Working from home
- Extra or extended breaks
- Disabled or accessible parking
- Reduced duties
- Adaptations or equipment required

Some people had their reasonable adjustments 'forgotten' about fairly soon which impacted their ability to perform well in their role and some had already been subject to absence management procedures with the accompanying stress that can bring. There were clear instances of likely disability discrimination within 7% of these 73 people. With disability being a new feature of the lives of people with Long Covid there is potential for this figure to be greater given the newness of the situation.

The impact of being refused reasonable adjustments has meant a reduction in hours, poorer competency, further absence, worsening symptoms, and ultimately for some, unemployment or a change of role.



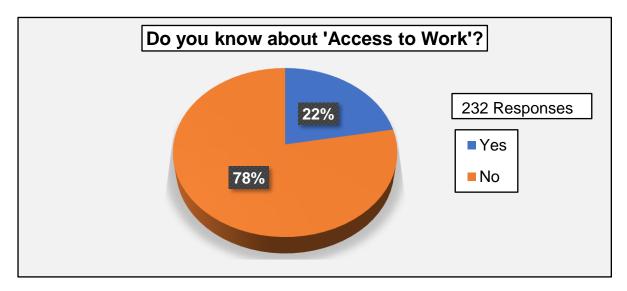
It should be noted that the Scottish Government <u>Coronavirus (COVID-19): fair work</u> <u>statement</u> stipulates that supporting flexibility, is critically important for disabled workers, and discussion with employees is recommended.

Facilitating flexible working arrangements, including homeworking

Homeworking is a vital part of the public health strategy and remains the default position wherever possible. Supporting flexibility is crucial, given the exceptional strains some workers will be experiencing. This will be critical for some disabled workers, and for those with caring responsibilities – particularly women - to whom the balance of caring still too often falls. Employers should offer homeworking and other flexible working arrangements which help people to balance work with care whilst protecting incomes and mitigating health risks. Individual health circumstances should be considered through effective risk assessment, and discussed with employees, giving particular attention to those in high-risk groups, vulnerable or shielded workers, or those living in vulnerable or shielded households. Flexible working practices benefit both employees and employers by raising or sustaining productivity, staff morale and loyalty which can support business and the economy in these uncertain times.

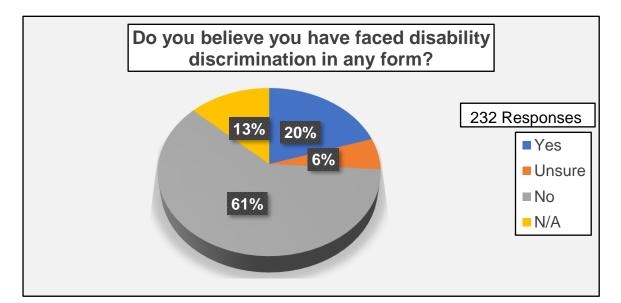
Access to Work

Most people had not heard of Access to Work with only 1% previously having used this service. The main positive use of Access to Work was that 3% of people used taxis to and from work to help manage fatigue. Another 1% wished they had known about it before unemployment and a further 1% were planning on applying. With only 6% of people engaging positively with Access to Work and 20% of people feeling they have faced disability discrimination, the comment, "I do not trust that I won't be discriminated against if I involve access to work" is perhaps justified. A large proportion of people are still unfit for work therefore this is less likely to have arisen for them at this time.



Disability discrimination

Disability discrimination comes in many forms and for people with Long Covid, new to the world of disability, it can be very difficult to spot signs and red flags of discrimination unless acutely aware of what they are. Bearing that in mind, for 20% of people to have responded saying they believe they have faced disability discrimination, it must be noted. We know that a large proportion of people are yet to return to or sustain a return to work, therefore this number could well be higher.



"Yes, I definitely had discrimination from various staff members which was humiliating and really upsetting. My employer was making the situation much worse due to deliberately piling on my workload and leaving me on my own which made it impossible to keep up with and get my job done, creating a lot of stress which concluded with me being forced into resigning from my job after 20 years."

"Yes, I know I have. Was refused a move of classroom and told I would sooner be provided with a mobility scooter. Pursued a grievance and before the final meeting, my employer agreed to my request."

"Yes, I had to leave my previous position due to them not following my adjustments and deliberately giving me visits at the top of flat blocks with no lifts. I didn't resolve it and knew it wasn't sustainable, so I moved role".

"I was told that normal people have 10 days off with covid and that I would be looking at my employer taking me down the capability route."



Long Covid Scotland: Report on Employment Questionnaire March 2022



"Yes. I received a disciplinary for a mistake made, which was caused by fatigue pain and difficulty thinking."

"Yes, because my council's phased return policy is a one size fits all and doesn't seem to be able to be flexible and meet differing needs."

"Yes, through lack of understanding and willingness to make necessary adjustments."



"Yes. My workload has actually been increased since my return to work, I believe, to encourage me to resign. Management hasn't supported me and feel that I'm not valuable anymore as I dared to say I was struggling with my workload."

"Yes, during lockdown to going back had to file a grievance to work from home during level 3 to 4." "Yes, and currently in grievance process, they have made settlement offer but minimal. Considering tribunal - currently with ACAS."





Occupational Health

Input from Occupational Health (OH) has been reported to be mainly in the form of phone calls or online meetings likely due to restrictions throughout the pandemic. Most experiences of those people able to receive input from Occupational Health have generally been supportive with recommendations for phased returns and reasonable adjustments being made.

Some people had difficulty with employers agreeing to make a referral, with waiting times for appointments and on a few occasions OH input was not sought until after work had recommenced which placed the employee at a disadvantage.

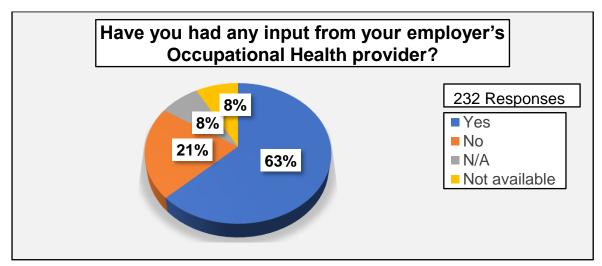
As Occupational Health is paid for by the employer and the supportive recommendations made are suggestive it seems to fall to the employer to decide which reasonable adjustments to follow and for how long, even though ACAS states differently.

"The employer or their HR manager and the employee should agree on a plan for how long this will be for." <u>ACAS</u>

Some people were referred to physiotherapy and a small handful of people have had access to extended services such as local or employer-based Long Covid services. This has mainly been for staff from a small number of NHS boards where good practice has been evident in supporting staff.

At the other end of the spectrum, smaller employers and those who are selfemployed have had little to no input from Occupational Health leaving them to flounder through lack of advice on how to be supported to return to work.

It is important to note that a 'one-size-fits-all' approach by many employers choosing to ignore OH recommendations has led to the failure to support individuals and their needs. The needs of an individual may be based on many components not least the symptomology and length of absence.



Lack of Occupational Health support leads to situations like this:

"I got Covid a second time and I was quite sick but returned to work fast as I was afraid to be off again. I feel like I have let my colleagues down with the first long Covid absence. I push forward and pretend to be ok, but I get brain fog and I always feel shattered. I also fear Covid-19 and it frightens me that there's no mandatory masks in classrooms as both times I caught Covid."



Here are positive experiences for workers of the NHS:

"I work for the NHS, so my sickness was not used as part of my sickness record, and I was assessed regularly by Occupational Health."

"Lothian NHS occupational support has been wonderful I don't know what I would have done without [person's name]."



Absence Management

The way that management of absence is carried out has a direct impact on job security, sick pay and salary which is why this question generated so many extended responses. Receiving an income to afford basic needs, maintaining a similar quality of life financially despite health deterioration, feeling reassured that mortgage or rent payments are covered and knowing that a job to return to is there assists with overall wellbeing by reducing these specific as well as conventional stressors. This is particularly important as many people expressed that the NHS waiting times and lack of action by the Scottish Government mean that they are spending longer off sick while healthcare appointments are sought. People with Long Covid need treatment and improvement in symptoms before being able to return to work. The issue of waiting times for NHS care and both the need for ongoing *Special Leave*/extended sick pay for people with this new disease is inextricably linked.

Scottish Government Coronavirus (COVID-19): fair work statement

Paying workers while they are sick, self-isolating or absent from work following medical advice relating to COVID-19

No worker should be financially penalised for following medical advice. Any absence relating to COVID-19 should not affect future sick pay entitlement or other entitlements like holiday or accrued time. It should not result in formal attendance related warnings or be accumulated with non-covid related absences in future absence management figures. This may require flexibility in standard absence/attendance management arrangements.

The most positive responses regarding absence management were from NHS professionals benefitting from *Special Leave* who have been protected from regular absence management procedures or reduction in salary although worry exists about a possible end date to this provision. Whilst some people have found their employer supportive or have not reached trigger points for absence management, a great number of people feel extremely stressed and concerned about their ability to continue to earn with increasing numbers now on half-pay or SSP alongside benefits. *Special Leave* has provided clear benefits to recovery without overarching stressors of absence management or reduction in salary.

"Protected, this far, from absence management procedures as NHS staff: On full pay due to Special Covid Leave policy. The uncertainty of when this will end is very stressful as I know then that the pressure will start."



"Invited to pop into work to see everyone which turned out to be an informal welfare meeting. Felt blindsided by this. Met at the door and was herded into a meeting room like a criminal. Then had to go through every conversation we've already had. I've been waiting over 3 months for an appointment with Long Covid Clinic so unable to offer any further developments."



"I have faced two absence management meetings and was facing a capability meeting before I decided to take a career break. I wasn't given much option, at either of these meetings, either return to work, take redeployment or a career break. There was a lack of empathy from HR with regards to what I've been through and how I was having to face these meetings even though I contracted covid through work. These meetings were so stressful and impacted on my symptoms greatly. The stress and worry of possibly losing my job or not eating was constant."

People remarked that employers are not believing their diagnosis despite it featuring on a Fit Note and this has resulted in gaslighting during meetings and being made to feel like an inconvenience.

"So far I have been made to feel guilty by senior management and like I was inconveniencing them."

"My former employer kept trying to bully me into coming back to work, even though I was unable to perform my duties as a butcher."



"Meetings and threatened with council procedures."

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Some people decided to resign from their roles due to the stress of going through absence management procedures or to protect their future career options while a sizeable amount of people remain highly concerned about being able to qualify for ill-health retirement. Redeployment has been another option to cause concern as the brain fog within Long Covid makes learning new skills and reapplying transferable skills more challenging. Some people are aiming to take an unpaid career break, yet this option is not suitable for all and does not provide any income.

"At the job I had when I first came down with long Covid I was put through Aberdeen City Council's standard procedure. Rather than deal with the final stages, I felt it was easier to resign."

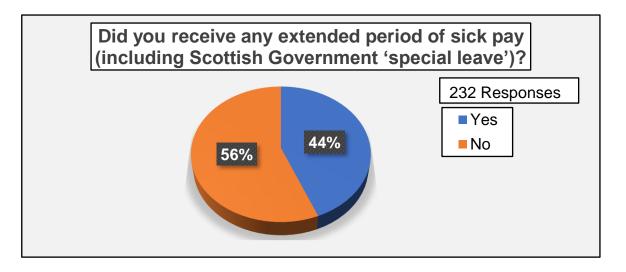
"Has not affected me as I had to resign from teaching due to Long Covid anyway, but absence management procedures are triggered by days absent over a specific period and Glasgow City Council's policy would have ended my career under capability had I been able to return. So, I knew it was impossible and resigned to protect my employment record in case I am ever well enough to work again".



"...if I am unable to sustain phased return I believe I will be taken down capability to route to redeploy or for ill-health retirement."

There has been great variation in absence management, from managers who are unsure of how best to support people and those who have failed to timeously implement Occupation Health advice. Sometimes company policy has not been followed putting employees at an unfair disadvantage. Equally, some public sector workers have consistently benefitted from <u>Coronavirus (COVID-19): fair work statement</u> whereas council workers across the board seem to have not had this applied to them placing them at an unfair disadvantage.

"Special leave until Feb 22. Now on normal absence management, forcing a return to work in June or will be forced onto half pay over summer holiday (school teacher cannot affect holiday dates)"



"Was initially on special leave. Now I am on absence leave and following council procedure. (Full pay then half pay) knowing meetings will be held soon to discuss this and my lack of recovery. The demands this has put on me have changed my anxiety levels greatly. I am still waiting on referrals to NHS and feel punished because of it, to the point I may lose my job due to something I contracted at work."

"Initially off on Special leave. Now changed to sickness procedures. Huge impact as now worrying about the ability to return to work based upon their absence management expectations. Not sure if this means I will have to leave my job. Also worried about finances and impact this will have on the family."



Out with the public sector, we must not forget those who have had to face more dire financial consequences and those who were self-employed and had to close their businesses.

"We also know that many disabled people feel forced to leave employment and the labour force, due to a lack of access to appropriate and timely support should they acquire an impairment or health condition, or if the impact of an existing impairment intensifies."

A Fairer Scotland for Disabled People: Employment Action Plan, page 15

The greatest concern by far regarding employment is the reduction in salary that people with Long Covid are facing. Due to the unending and relentless nature of Long Covid symptoms, as mentioned earlier, one of the most common adjustments in being able to sustain a return to work is to reduce hours. The reduction of working hours out with a phased return directly reduces take-home pay for individuals. With no known treatment for Long Covid and the potential for symptoms to continue indefinitely, individuals with Long Covid will only be able to remain within part-time work where possible and according to their symptom management which puts them at a substantial disadvantage. With other conditions and diseases, often treatment alleviates symptoms allowing a fuller return to work, yet at this time this cannot be said for Long Covid. The considerable loss of earnings is of huge concern, especially given the misogynistic nature of the disease and that many frontline workers caught Covid-19 in the line of duty.

"...even though I'm on a phased return will go to nil pay next week and only be paid for the hours I do (currently 15). I have managed with savings etc but the move to nil pay has me very worried and am also v concerned about what happens at end of the phasing period if I can't manage full-time hours by then or be able to do my job fully - what will happen? Not sure if I will lose my job or be moved to another role. I feel my manager is angling to get me moved."

"I have been off sick since September and ran out of sick pay. I'm currently living off savings and SSP."

"Told that if I feel like I am unable to do my job my only option is to reduce my hours which would reduce my pay."

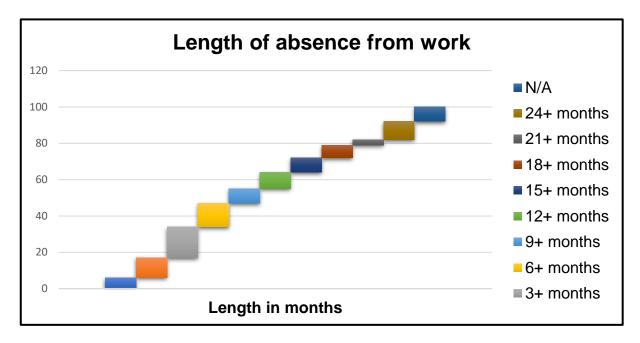
"Basic SSP only, denied I had long Covid despite this being on Fit Note."

"Military absence, not effective and could eventually be medically discharged"



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The length of absence from work has a correlation with the amount of sick pay left and the uptake in benefits. Below, you will see the increases in numbers at three months relating to the Omicron variant and similarly with earlier surges.

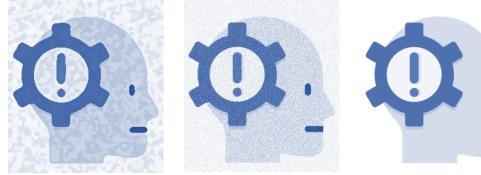


We asked about peoples' benefits status and there has been an 8% increase in Universal Credit/Tax credits claims, a 9% rise in Employment Support Allowance, 2% more claiming housing benefit, and 3% now eligible for council tax support. These figures only stand to rise without further financial measures to protect jobs being in place.

The lengthy forms and assessment procedures for the likes of Employment Support Allowance, Personal Independence Payment or Adult Disability Payment are extremely challenging for people with an energy impairment. This topic could form a whole report on its own.

"I did receive ESA, but they have now decided I am fit to work. I will be taking them to a tribunal, but it is very hard with continued brain fog and fatigue."

Those who have become unemployed, been redeployed or changed career path face new challenges. Brain fog impedes new learning and a change of job or employer means that there will be no sick pay initially as it takes time to build it up these entitlements.



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Barriers to returning to work

The biggest barrier to returning to work for people with Long Covid is their ongoing symptoms and lack of treatment stemming from excessive NHS waiting times and lack of conclusive biomedical research in the UK. People feel trapped within this period of waiting where they do not see any improvement in symptoms and during this time, they consume any available sick pay/leave. Those who have already used all available leave and sick pay, are forced to live off any available savings and then move on to being reliant on a range of benefits. Those who can return may only be able to manage part-time work.

"Not being able to work more than 14 hours, working is slowly killing me, the strain is affecting my recovery. But I need to eat."



"Ongoing symptoms, financial implications due to potentially having to reduce hours permanently."

Nurses face unique problems regarding registration and updating skills/qualifications.

"I'm due to renew my registration as a RGN in April but I will be unable to meet the criteria for this. I will therefore lose my registration."

"As a qualified nurse, many of my mandatory training requirements have expired. My registration is now at risk."



Similarly to nurses, teachers have public-facing active roles and face significant challenges to try to meet the demands of their role.

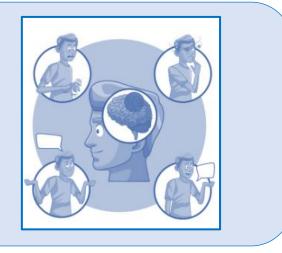
"I can't even begin to think about being the way I am in a nursery environment with 30 children needing my continuous support - physically and emotionally. I'm not sure if I will be able to return to doing the job I love."



"Ongoing symptoms, especially fatigue and how I can manage this as it's very up and down, teaching is a high energy job that is not doable unless 100% well. If I suddenly empty my energy battery that sometimes comes from nowhere, I need to rest immediately, or it could result in a relapse - this is difficult to manage in teaching."



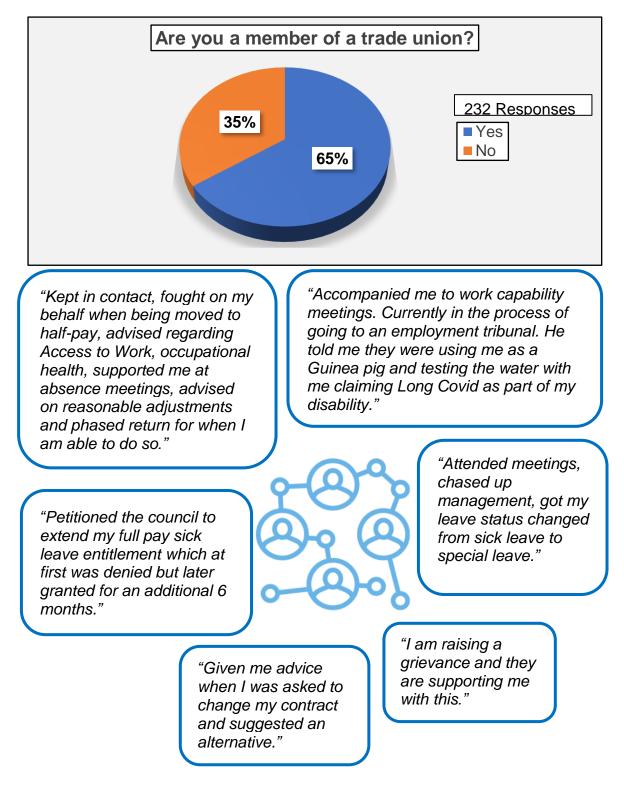
"I cannot return to the post I had as a special needs teacher nor can I return to mainstream school. The disabilities acquired post covid mean I would be unsafe to be child facing without significant supports. Functional Neurological Disorder, post covid, requires specific working conditions (for example no patterned flooring)."



Roles that require overnight working, lone working or working outside in all weather conditions for long periods are not possible for a person with Long Covid. People searching for a new role have exclusive challenges in finding a position that suits shorter shifts, fits around childcare commitments and allows for effective symptom management.

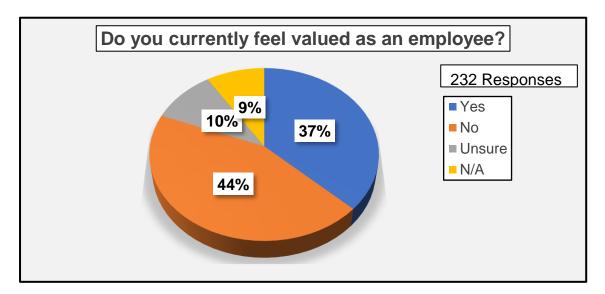
Trade Unions

Even though only just over two-thirds of people were in a trade union and some people have chosen not to call on the services of their union, for those who have, the experiences are that people have been supported effectively by their union. Union representatives have provided advice, representation at meetings, assisted in making financial improvements for people and discussed return to work plans.



Fair Work Convention

We asked, "Do you currently feel valued as an employee?" and the results are clear that the majority of- people with Long Covid do not feel valued.



"Not at all. HRs indecision and stressful dealings impacted my recovery, the CFS clinic's actual words to me."



"No. I feel like I'm no longer seen as a human being, just a drain on resources."

"No, because I am terrified to ask for reasonable adjustments, I've seen others with longterm illness discriminated against and dismissed ultimately."



"No. Not kept in the loop. Just because I have become disabled I have been treated differently and face discrimination which is not acceptable. Councils and their employees should know better."

"No, teachers are not valued."

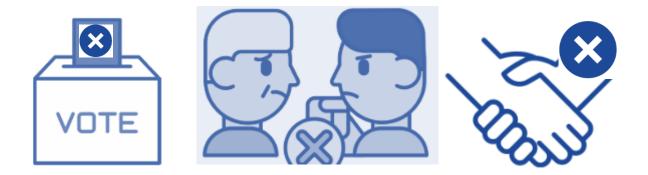
"By team yes but by the local authority, treated appallingly."

"Absolutely not! If you're not a favourite of the boss you get extra work thrown at you while her pals get time off for nothing. I am a teacher."



"No absolutely no empathy shown from my employers. All they're interested in is me being back in school to provide PPA cover."

"Not by the government or council. I felt put at risk like my life was expendable."



"No. Considering I caught Covid at work from a child I now feel that I am being pressured to return to work by the council. My Head Teacher has been really good but he has to follow procedures. I personally feel that as covid mitigations are being removed that anyone with Long Covid is being left behind and almost judged for being ill." "No, despite clearly catching covid at work (March 2020) as 6 of my patients and another staff member caught it, my work will not accept it as occupational, haven't done a RIDDOR. When I came back, they were deliberately ignoring my adjustments. Since moving positions despite having another long-term condition that OH says puts me at high risk, I have not to see covid patients, but I still keep getting sent to them which resulted in a second covid infection in February 2022."

"No. I worked on the frontline during the pandemic with very little PPE. I just feel discarded. I gave my health to help others & now I'm just a number."

"Employer denies I could have caught this at work (despite being NHS frontline). I feel in a precarious position and that employer would prefer me to resign."



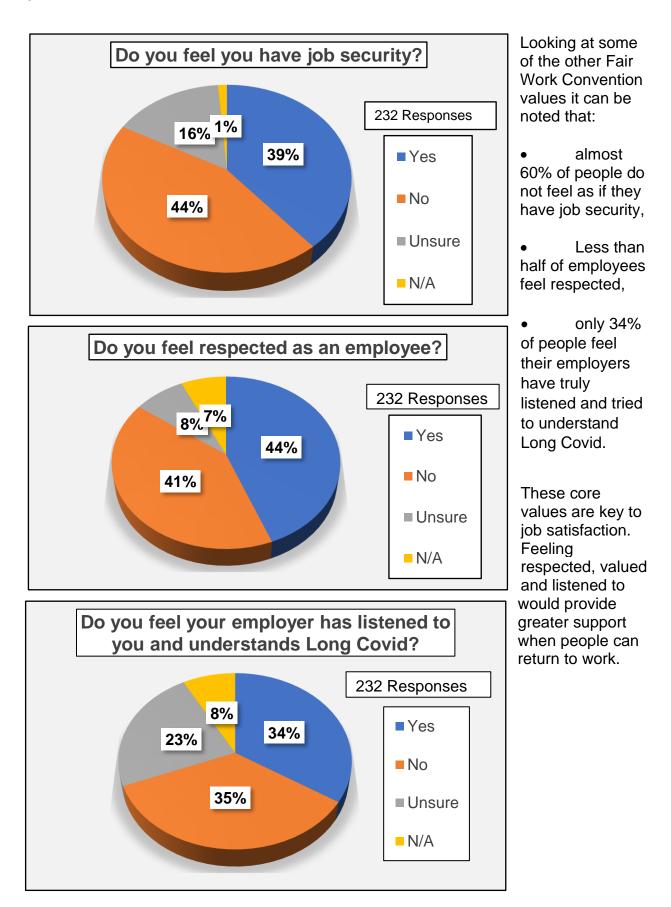
"I got covid during lockdown in a face-to-face patient role so most likely caught it at work. I followed all absence management policies, advised my manager before each FIT note was due to expire that I would be seeking a new one as still unfit, updated him after GP consultations, sent in FIT notes on time and was told by my manager that my absence was not being put down as covid and as I had already been told by this by another manager it was going towards my sickness absence and I would be moving onto half pay. I feel that all my years dedicated to my job have just been swept away. Disgusted and upset."







"I did feel valued as a loyal hardworking employee for the company I worked for, for 7 years. Then I got Covid - my GP considers I contracted this at work in the pharmacy at a time when patients were presenting with Covid symptoms frequently as GP surgeries would not see anybody at this point in March 20. There was also no PPE, social distancing etc in place at that point. Subsequently, I took ill. My employer was not supportive throughout my absence and my whole absence was mismanaged. Ultimately led to my dismissal. I feel extremely let down that a large high street chemist who I was proud to work for has made me feel so undervalued not only as an employee but also now as a person."



CONCLUSIONS

The devastating impact of the pandemic has created mass disability on a scale not seen in most people's lifetime, the brutal repercussions of Long Covid affecting all spheres of life, not least employment.

The ability to work has a direct impact on well-being, self-worth, plus overall mental and emotional health. It is well established that stress can impact wellbeing, and the lack of treatment through defined care pathways arising from lack of funding by The Scottish Government alongside the removal of the Coronavirus Fair Work Statement which 44% of people have benefitted from places people with Long Covid in a dire financial situation. Being unable to work, running out of normal sick pay and facing absence management procedures that do not take account of Long Covid's lack of treatment or relapsing and debilitating patterns, creates undue stress which impacts overall wellbeing and recovery times for people with Long Covid.

Given this is the first report on Long Covid within Scotland it is prudent to compare findings to prior reports such as the <u>TUC's Workers' Experiences of Long Covid</u>. The comparison reveals that 54% fewer people in Scotland returned to normal work hours, that 10% more people in Scotland are now unemployed and 12 % more people in Scotland experienced poor treatment or disability discrimination due to Long Covid. These statistics are unacceptable and something which the Scottish Government must take seriously and urgently act upon.

Concern	Long Covid Scot	TUC	Difference
Returned to work with normal hours	3%	57%	54%
Now unemployed	15%	5%	10%
Poor treatment / Disability discrimination	20%	8%	12%

Whether or not such findings are compounded by employers' disbelief of Long Covid does not make this acceptable. People with invisible illnesses must be believed and supported properly. Many employers have long inroads to make to improve working conditions for people with Long Covid. This is emphasized by only 37% feeling valued, 44% feeling respected, 34% feeling listened to and having their Long Covid understood and 39% feeling they have job security.

Employers need to up their game to keep valued, experienced and committed staff employed and The Scottish Government need to bring their aspirations stated in <u>A</u> <u>Fairer Scotland for Disabled People: Employment Action Plan</u> to fruition. With only 22% knowing about Access to Work and 39% being aware of reasonable adjustments in relation to the Equality Act 2010, these damming statistics openly depict the state of employment for people with Long Covid in Scotland. The picture is not pretty. Immediate measures are needed to stop the estimated 155,000 people, many of whom are key-workers, from falling out of employment. The CIPD published <u>Working with long COVID: Research evidence to inform support</u> yet guidance does not seem to be implemented, much like the tails heard from people about Occupational Health recommendations being a pick and mix scenario.

Therefore, let's not use 'stress' and 'mental health' issues against people with Long Covid who are undoubtedly financially up against a mountainous climb in fighting for their loss of employment, earnings, health and potentially seeking grievances and tribunals to right these wrongs.

What the heart of The Scottish Government seems to fail to realize is that Long Covid has a cost. The cheaper cost would be to provide immediate healthcare treatment offering a resolution for known disease elements however what appears to be happening is that lack of access to medical care through underfunding and a refusal to directly champion Long Covid Clinics means that the finite period of sick pay and employers tolerance is expiring, leaving those disabled fighting for treatment, jobs, benefits, and housing. With such cost-cutting ambitions, the current Scottish Government cannot see the wood for the trees with Long Covid costs set to rise further through unemployment, social care, and multiple benefits and housing claims.

RECOMMENDATIONS

1) The continuation of the Scottish Government Coronavirus Fair Work Statement.

The Scottish Government and STUC agreed to the <u>Coronavirus (COVID-19)</u>: <u>fair work statement</u> yet it is clear that it is not being equally applied throughout all public sector organisations. We recommend that when this statement is reviewed that it is extended so that further provisions are put in place to support those who served on the frontline and that are unable to return to work.

2) Proposed Scottish Employment Injuries Advisory Council Bill

Given the disabling nature of Long Covid and that many people are left unable to work, we recommend that the Scottish Government work to pass this Bill through Scottish Parliament to ensure that a forum for discussing Long Covid as a disability within Scotland exists.

3) Long Covid should be a disability under the Equality Act 2010 The Scottish Government should back calls from the All-Party Parliamentary Group and fellow groups to name Long Covid as a disability under the Equality Act 2010.

4) Increase employment rates for disabled people through measurable actions.

Unemployment rates for disabled people are significantly higher. Currently, a large amount people with Long Covid who are now disabled, many of whom are still in employment need to be nurtured back to their jobs once able to do so. There are policies and frameworks in place which need to be consistently implemented across the board. Evidently more needs to be done to ensure that disability discrimination arises far less frequently.

5) Disabled workers' reasonable adjustments

People with Long Covid need to be better informed about Access to Work and reasonable adjustments. Flexible working patterns as a reasonable adjustment under the Equality Act 2010 need to become commonplace for disabled workers from day one, including key-workers with public-facing roles.

6) Absence management

Policies to monitor long-term absence and disabilities must be reviewed and updated to ensure that they are fit for purpose, that they are inclusive, and that they meet the requirements of an Equality Impact Assessment.

7) A holistic response from the Scottish Government is required.

The act of pulling away the Coronavirus Fair Work Statement before appropriate healthcare provisions are rolled out in the current climate of excessive NHS waiting times would be a callous move lacking coordination from the Scottish Government. Reciprocation for keyworkers must be central to policies and decision making at the heart of government.

8) Workers with disability must be valued and listened to.

Invisible disabilities and Energy Limiting Conditions need better recognition. Employers need to view people as individuals, and ensure the two-way meaningful communication underpins decision making. The wider issue of the value of disabled workers, their ability to earn and their capacity to continue to share skills or develop new skills must be embraced to form an inclusive society.

9) Statutory Sick Pay and benefits must meet a living wage.

Current rates of Statutory Sick Pay need to be increased to a living wage. The benefits process for people with energy impairments or disabilities needs to be reviewed to accommodate their holistic needs, and this includes the new Adult Disability Payment being rolled out by Social Security Scotland.

10) Equal access to Occupational Health

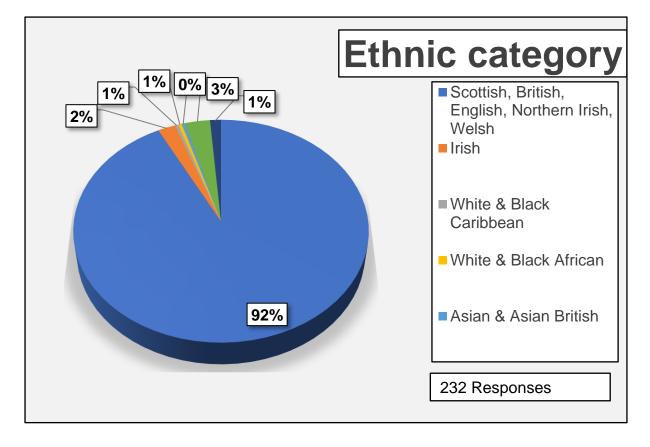
We recommend that the Scottish Government set up an Occupational Health service to benefit smaller employers and the self-employed to ensure fair access to specialist knowledge.

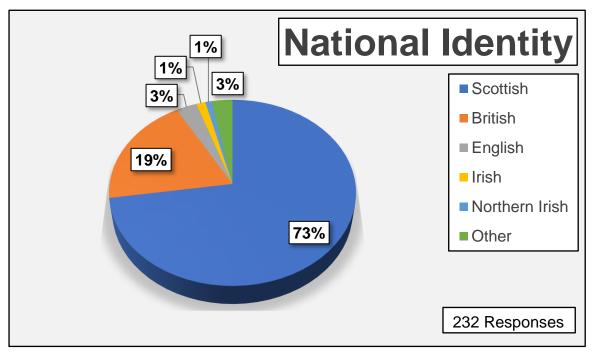
11)Ensure that the voice of lived experience is included in public inquiries.

Lived experience of Long Covid and the subsequent treatment of people with Long Covid must be considered in any ongoing or continuing public inquiry.

APPENDIX 1

DEMOGRAPHICS





APPENDIX 2

CONSENT

Employment Questionnaire March 2022 CONSENT			
We are collecting information about Long Covid experiences in Scotland. We will use this data to inform our ongoing work to influence and inform academics, clinicians, policy makers, politicians, researchers health and social care services and raise awareness of Long Covid in the general media. You can read our current manifesto here: <u>https://www.longcovid.scot/manifesto</u> The information we collect will be stored securely on Google for the duration of campaign activity. We are aware that people may have privacy concerns and therefore your name and contact details will not be collected. If you do wish to contact Long Covid Scotland Action Group about this survey or anything else please email: comms@longcovid.scot			
Iongcovidscot.employment@gmail.com (not shared) Switch account * Required			
Please read the following statements and check the box to indicate your * agreement:(You must tick each box to indicate your consent to take part in the survey)			
I understand that my questionnaire will be used to inform the work of Long Covid Scotland			
I understand that my questionnaire is anonymous and that I will not be identifiable.			
I understand that results and individual quotes may be published, however, it will not be possible to identify me in future publications.			
I understand that finding may be shared with policy-makers, researchers and health agencies however, all information will be anonymous and that I will not be identifiable.			
I consent to take part in this Long Covid Scotland Survey			
Do you live in Scotland? *			
Yes, please complete the rest of the questionnaire			
No, Thank You for taking time to complete this survey, but we are looking for responses from people living in Scotland to better understand their experiences and needs for support.			

APPENDIX 3

QUESTIONNAIRE

1. Are you resident in Scotland? *
O Yes
○ No
2. Are you currently employed? *
O Yes
⊖ No
3. Have you lost your job due to Covid-19 or Long Covid? *
O Yes
⊖ No
Yes, but for another reason
4. Have you resigned from your job, taken early retirement or requested a career * break due to COVID symptoms or Long Covid?
O Yes
⊖ No
O Career break
O Retired
O Resigned
○ N/A
Other:
5. Are you currently *
O off ill?
◯ back at work?
O unemployed/unpaid carer

Long Covid Scotland: Report on Employment Questionnaire March 2022

	e you previously tried to return to work? How many times have you evented it from being successful?
Your answer	
7. If you are ba	ck at work, how has that impacted your symptom management? *
Your answer	
8. Would you s Yes No N/A	ay you are able to sustain your current pattern of working? *
9. Were you giv	en a phased return? "
9. Were you gi	PHASED RETURN TO WORK
9. Were you giv	
O Yes	

10. Did you have to use accrued annual leave as part of your phased return? * Yes No N/A
11. Can you break down how your phased return was tailored? e.g. reduced hours, reduced days, amended duties, flexible working, assisted travel to and from work, how many weeks was your return planned Your answer
 12. Do you know what Reasonable Adjustments are in relation to the Equality Act * 2010? Image: The Equality Act 2010 Yes No Unsure
 13. Have you asked your employer for Reasonable Adjustments? * Yes No N/A
14. Which Reasonable Adjustments have been agreed with your employer? Your answer

15. How have these Reasonable Adjustments assisted you?
Your answer
16. Were you denied any Reasonable Adjustments?*
Ves
○ No
○ N/A
17. Were you given the justification for the refusal of these Reasonable * Adjustments in writing?
O Yes
○ No
○ N/A
18. Which Reasonable Adjustments were you refused and why?
Your answer
19. What impact has the lack of these (refused) Reasonable Adjustments had on your ability to work?
Your answer

20. Do you believe you have faced disability discrimination in any form? If you * have did it resolve or is it ongoing? Feel free to expand. <u>https://www.equalityhumanrights.com/en/advice-and-guidance/disability-discrimination</u>
Your answer
 21. Have you had any input from your employer's Occupational Health provider? * Yes No N/A My employer does not offer Occupational Health
22. What input have OH had? e.g. online call, face to face, suggested physio, made suggestions about how and when to return, made suggestions about Reasonable Adjustments Your answer
 23. Do you know about 'Access to Work'?<u>https://www.gov.uk/access-to-work</u> * What is Access to Work? Access to Work is help you can get from docents Pha to do your yos. Between get the help if you as the docent of the get in offer a constraint of the get in off

24. Have you applied for 'Access to Work' and how has it helped?
Access to Work can help pay for: • Equipment to help you do your job and make things easier to • Changies to equipment so you • Changies to equipment so you • Travel to work if you cannot use public transport • A job costs • A job costs • Your answer
25. What absence management procedures have you been subject to? Tell us * about the impact have they had on you. Your answer
26. How long have you been absent from your job? * Your answer
27. Are you a member of a trade union? * Yes No
28. What has your trade union done to support you? Your answer
29. Did you receive any extended period of sick pay (including Scottish Government 'special leave')? Yes No

 30. Do you received any means tested benefits that you previously were not eligible for (due to reduction of sick pay or loss of earnings)? Tick all that are applicable. Universal Credit Employment Support Allowance Income-based Jobseeker's Allowance Income Support Pension Credit Tax Credits (Child Tax Credit and Working Tax Credit) Housing Benefit Council Tax Support Social Fund (Sure Start Maternity Grant, Funeral Payment, Cold Weather Payment) I do not receive any benefits I have had no change in benefits since developing Long Covid
31. What barriers do you see in preventing your return to work? e.g. ongoing * symptoms, waiting treatment, neogtiating new hours, redeployment. Your answer
32. Do you currently feel valued as an employee? Why or why not? * Your answer
33. Do you feel you have job security? Why or why not? * Your answer
34. Do you feel respected as an employee? Why or why not? * Your answer
35. Do you feel your employer has listened to you and understands Long Covid? * What could they do to improve? Your answer

About you
36. What is your age? *
Under 25
26-34
35-44
45-54
55-64
65 and over
Prefer not to say
37. What is your gender? *
O Female
O Male
Non-binary
O Other
O Prefer not to say
38. National identity *
Choose -
39. Ethnic category *
Choose 👻