

# Working well?

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How the pandemic  
changed work for  
people with health  
conditions

June 2021



in partnership with:

# About us

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## **Centre for Ageing Better**

The UK's population is undergoing a massive age shift. In less than 20 years, one in four people will be over 65.

The fact that many of us are living longer is a great achievement. But unless radical action is taken by government, business and others in society, millions of us risk missing out on enjoying those extra years.

At the Centre for Ageing Better we want everyone to enjoy later life. We create change in policy and practice informed by evidence and work with partners across England to improve employment, housing, health and communities.

We are a charitable foundation, funded by The National Lottery Community Fund, and part of the government's What Works Network.

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## **Institute for Employment Studies**

IES is an independent, apolitical, international centre of research and consultancy in public employment policy and HR management. It works closely with employers in all sectors, government departments, agencies, professional bodies and associations. IES is a focus of knowledge and practical experience in employment and training policy, the operation of labour markets, and HR planning and development. IES is a not-for-profit organisation.

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# Key message and recommendations



The pandemic has not only widened the disability employment gap and the age employment gap, but also the gap between those in good and bad employment. Our research, conducted over the first year of the pandemic, indicates that employers who were already supportive of workers' health stepped up during the crisis.

But, in the stories we heard, those who were not supportive continued to fail – to the detriment of already vulnerable employees. To ensure a fully productive recovery, the government must recommit to its work and health agenda, incentivising and supporting more employers to properly support the people who work for them.

## That means government should:

- Bring the key measures from the proposed Employment Bill before Parliament without delay: ensuring that the right to request flexible working from day 1 is included, and introduce a single-enforcement body for employment rights.
- Commit to the ambitious proposals put forward in the 'Health is Everyone's Business' Green Paper – including plans to introduce financial incentives for Small and Medium Enterprises (SMEs) who support workers while on long-term sickness absence.
- Increase pace of reforms to improve access to occupational health.
- Increase the rate of Statutory Sick Pay (SSP) in line with European averages.
- Make sure that the specific needs of disabled over 50s – who face an insidious mix of ableism and ageism – are included in the forthcoming Disability Strategy.

- Include line-management training in the subsidised ‘Help to Grow: Management’ training offer to SME leaders announced in the budget.
- Make sure that the Plan for Jobs works for older and disabled workers, by setting service standards for both groups.
- Not hesitate to re-instate the shielding category if vaccine-resistant strains of COVID-19 begin to spread widely, to protect vulnerable workers – and ensure that shielded workers can continue to access support.

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### Meanwhile, employers should:

- Create a culture that is explicitly anti-ableist and anti-ageist.
- Actively try to learn from the natural experiment of mass remote working.
  - Find out what practices staff did (and did not) put in place in order to manage the rapid shift to remote working, and adopt them into permanent policies and ways of working.
  - Use Ageing Better’s flexible working toolkit<sup>i</sup> to structure conversations with staff about their future working arrangements.
- Invest in line-management training, now – and make sure your line managers are implementing your policies.
  - This should include training on how to talk about health at work and how to understand and implement related policies and adjustments. But universally good line management practices – listening, offering

<sup>i</sup> See Timewise (2020) Flexible working for over 50s – A toolkit for employers. Centre for Ageing Better. Available at: <https://www.ageing-better.org.uk/publications/flexible-working-over-50s>

praise when warranted and understanding when things go wrong, helping people to develop – are also key for supporting workers with Long Term Conditions (LTCs). Line managers need: training so that they know what good looks like; enough time to adequately support their line managers; and clear pathways to refer staff when there are problems to address.

- Confront ageism and age-bias in your recruitment processes.
  - That means collecting and scrutinising recruitment data to investigate biases at different stages of the process, age-diverse recruitment panels, and removing age-stereotyped words from job advertisements. We will be producing further recommendations on how to make these changes via our Good Recruitment for Older Workers (GROW) project.
- Take explicit action to support the mental health of your employees.
  - Review existing policies and practices in light of any pandemic-related changes to the workplace, using staff feedback. Make adjustments – such as instating Wellness Action Plans, or offering counselling through Employee Assistance programmes – drawing on the wealth of resources available.<sup>ii</sup> Keep creating opportunities for employees to socially interact (if they want) – especially if greater remote working continues.
- Continue to offer support and protection to staff who are clinically vulnerable to the virus.
  - Follow safety best practice, carry out individualised risk assessments for those who are vulnerable, and continue to support home-working where requested.

<sup>ii</sup> A large collection of resources tailored to different contexts and conditions has been curated by Mind, at: <https://www.mentalhealthatwork.org.uk/>

# Findings summary



## Evergreen truths about health and work

- 1** Good line management matters just as much as adaptations and adjustments.
- 2** Work is a source of meaning and value for many people with Long Term Conditions (LTCs) – not just a financial necessity.
- 3** Part-time work is a key part of the solution for helping people with LTCs remain in work.
- 4** Stigma – from age and disability – prevents many older workers from disclosing their LTC to their employer.
- 5** All workers deserve access to decent sick pay.
- 6** Older workers with LTCs worry about ageism as well as ableism.



## What has changed over the past year?

- 1** Employers who provided good support prior to COVID-19 commonly continued that practice during the pandemic.
- 2** For those who could work remotely, doing so was often a positive change – but not for everyone.
- 3** The pandemic brought mental health challenges – but so will returning to ‘normal’.
- 4** Jobseekers with LTCs were worried about the rise of ageism and ableism in a competitive job market.
- 5** Shielding letters – while not perfect – provided clarity for many vulnerable workers and their employers.
- 6** The pandemic has given many older workers an opportunity to reflect on their future.
- 7** Participants were resilient – and even thriving – in the face of the pandemic, if the right support was in place.

# Context

**The Centre for Ageing Better works to create a society where everyone has the financial security, physical and mental health, housing and community connections they need to enjoy their later life.**

Good quality work can provide – or, at least, support – all of these things. But we know that both people aged 50 and over, and people living with LTCs and disabilities, face barriers to employment.

- In March 2020, 73% of people age 50–64 were employed, compared with 86% of people age 35–49 – giving an age-related employment gap of 13 percentage points.
- In the year to September 2020, 52% of disabled people age 16–64 were in employment, compared with 81% of non-disabled people – giving a disability employment gap of 29 percentage points.
- The disability employment gap is largest for those aged 50–64.
- Both of these employment gaps have grown by one percentage point since the start of the pandemic.
- During the course of 2020, disabled workers were significantly (1.5 times) more likely to move out of work than non-disabled workers.<sup>1</sup>
- Ill-health is not an inevitable part of being middle-aged. But as we get older, we are more likely to experience a long-term condition (or LTC). Forty-five per cent of those aged 50–64 report at least one LTC, compared to 28% of those aged 30 to 49

and 23% of those aged 16–29. And, as we age, we are more likely to experience multiple conditions.

- Ill-health pushes more older workers out of employment than any other factor: it is the most common reason given by people age 50–64 for being out of work.

Previous Ageing Better work has highlighted some of the reasons behind this: including the stress of disclosing a condition, and the multiplicity of conditions that complicate our health needs as we age. In 2018 we found that access to health and work support for older workers was patchy, and often not sustained.<sup>2</sup>

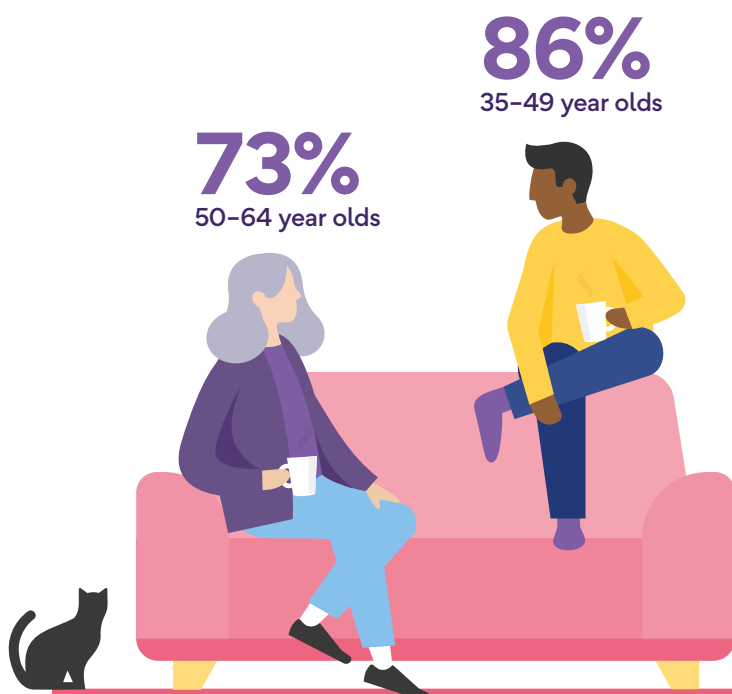
Prior to the pandemic, progress was being made in government on the Work and Health Agenda. The 2019 green paper ‘Health is Everyone’s Business’ offered proposals for concrete changes to improve access to occupational health and incentivise good employer behaviour. An Employment Bill was promised, with increased access to flexible work as one of its key features. From a government perspective, there was clear momentum towards more inclusive workplaces.

When the pandemic hit, we realised that this momentum was in jeopardy, even though the relationship between health and work was more topical than ever. We identified that the risks of the pandemic on older workers with LTCs were likely to be substantial. These included reduced employer ‘bandwidth’, a more challenging labour market, increased demand for employment support and worsening health. The changes that we



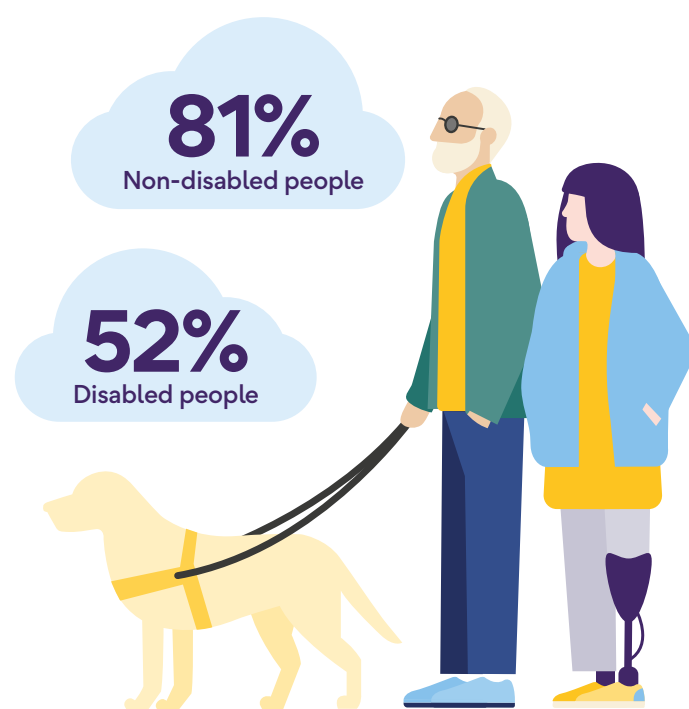
**March 2020**

**The age-related employment gap was 13 percentage points.**



**September 2020**

**The disability employment gap was 29 percentage points.**



were expecting no longer seemed as secure – but they were potentially more urgent.

We therefore commissioned the IES to follow a group of workers aged 50–69 with LTCs over the course of the first year of the pandemic. We wanted to capture a variety of experiences and understand – in a granular way – what their impact was.

A year on, this has given us an indication of how much the approach to health and work needs to change as a result of the pandemic.

The answer: we don't need a fundamental shift in direction, but we do need a shift in the speed of change. And at the moment, it looks like progress in government at least is slowing. The Employment Bill was entirely absent from the Queen's speech. We do not know how and when the measures it was supposed to introduce – including measures to expand flexible work eligibility – will come in. The 'Health is Everyone's Business' consultation closed in October 2019, but the government still has not published a response.

We need to urgently bring forward measures currently on the table. And we need a major step change in management capabilities and employer attitudes as well as supportive legislation, guidance and financial support for people on sick leave.

# Methodology

**We chose a qualitative methodology – designed to elicit rich case studies – as our way into these questions. We knew that the way that the pandemic impacted on people's lives, health and work would be complex and highly individualised. We did not want to flatten those experiences – we wanted highly granular, concrete insights which would indicate specific areas for change.**

**This paper is based on an in-depth research report produced by the Institute for Employment Studies, published alongside this one. A full description of the methodology can be found in that research report.**

IES adopted an in-depth and longitudinal qualitative research methodology consisting of two primary elements:

- Two interviews with twenty participants, aged 50 years and over, who have a long-term health condition or disability, conducted six months apart. A full list of participants, with their demographic and employment details, is included in Annex 1.
- Monthly prompted online journals to capture ongoing changes and experiences as lockdown measures are eased and individuals potentially return to work.

For each participant, the findings from the interviews and journals are summarised in an anonymous case study that illustrates their

experiences over time. These rich stories are fundamental to understanding this paper. They are not reproduced here, but should be read alongside this report.

Our case studies themselves are not generalisable to all older workers with LTCs – or even all workers with the same LTCs. Our case study was not fully representative of the population – in particular, men are significantly under-represented.

In this insight report, we pick out some of the key lessons that emerge from the research, and bring it together with wider work that has been published over the last year. This gives us a window into some of the issues that the pandemic has created, and the impact it has had. What follows is not an exhaustive list of all the ways in which COVID-19 has impacted work for people with LTCs – but a set of concrete insights into the way that some people have been affected, and the issues that will need to be addressed by government and employers.<sup>iii</sup>

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<sup>iii</sup> Mason B, Edwards M, Bajorek Z and Bevan S, (2021), The impact of COVID-19 on older workers with long-term health conditions. Available at: <https://www.ageing-better.org.uk/publications/working-well-how-pandemic-changed-work-people-health-conditions>

# Findings



## Evergreen truths about Health and Work

### **1. Good line management matters just as much as adaptations and adjustments**

Most of our participants reported receiving some kind of support from their employer. That commonly took the form of specialist equipment, such as a special chair, desk or keyboard – which is what often comes to mind when we think of ‘reasonable adjustments’. But it was flexibility in working hours and emotional support from their employers that the participants valued most.

Where that emotional support was lacking, it posed a problem for participants – before the pandemic, but particularly during it, and the changes it brought about. In some cases, this lack of support contributed to the exacerbation of participants’ ill-health.

Participants cited regular one-to-one meetings to discuss work issues, being asked how they were (and having the answer listened to) and showing patience as the kind of support they wanted. Research from the Institution of Occupational Safety and Health also lists clear communication about tasks and expectations, trust, praise and recognition as key forms of support for managers to provide.<sup>3</sup>

The culture and practice of the organisations participants worked in played a large part in dictating whether or not this support was available. But ultimately, these things – enabling flexibility and providing emotional support – often come down to line management.

Research shows that line management – and line managers – have a decisive impact on worker wellbeing, particularly so when that worker has a LTC.<sup>4</sup> During the pandemic, the role of line managers has become ever more crucial. They have been the main point of

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contact for remote workers, supported staff to return safely to the workplace and managed the increased workloads that the pandemic brought for many of our participants.

Our report contains many stories of great line managers, whose open and flexible approach made a real difference to our participants' working lives. **Laura's** (54; mental illnesses, osteoporosis) line manager, for example, was a case study in 'what to do':



**“My manager really understands. When I had time off last year for depression, she would check in on me to see if I was okay, there was never any pressure. When I am in work and I need to move around a bit to help with the back pain, she just says ‘do what is best for you’.”**

Many of our participants reported similar experiences to Laura's story, but some of our participants had dealt with poor line managers.

**Caroline** (over 60; arthritis, auto-immune condition, cancer) – a call centre worker – had a particularly raw deal:



**“I felt really let down by my manager, she did not understand the practices and policies the organisation has about sickness absence, and she offered no help or support about adjustments. She is young and does ask the ‘how are you’, but doesn't listen, or even try to understand the experiences that I face every day.”**

The lack of support she was given not only had a negative impact on her health but also on her work performance and productivity, due to the anxiety she was being caused. Her employers appeared to have policies and processes in place that should have

helped Caroline – for example, she was offered an occupational health assessment – but they were entirely undermined by the line manager's inability and unwillingness to act on the assessment's recommendations.

At 2018 survey by CiPD found that just a third of employers provided guidance and training for line managers to help them support staff with disabilities or LTCs. But more than half said that developing line manager confidence was the key challenge they faced in managing people with disabilities and LTCs.<sup>5</sup> Clearly there is a gap here – and demand.

Line managers need good training and support so that they know how to find out about and implement adjustments and flexible working arrangements. And they need the confidence to discuss health – physical and mental – openly. These skills are as valuable to all workers as they are to workers with health conditions. It was the 'human touch' that our participants valued so much and missed when it wasn't there.

## **2. Work is a source of meaning and value for many people with LTCs – not just a financial necessity**

Not all people with LTCs can or would want to work. But many of our participants – all of whom were in work at the start of the pandemic – reported that they really valued being able to work.

**Hannah** (56) – living with anxiety, depression, and back pain – expressed this vividly:

“I don’t want to be in a situation where I am told that I cannot work anymore, because I love to work and I love my job. I like having the satisfaction of knowing that I am helping and can listen to others as well.”



‘Work is really important to me,’ said another participant, **Mary** (60, Parkinson’s), ‘and I want to make sure that I can continue doing what I do when I can’.

Participants who had had some time out of work reported how much they valued returning to it. **Susan** (56; chronic fatigue syndrome) decided to look for work as she needed an income, but she found that work really helped her mental health as she feels part of a team and that she is contributing to the community.

For some, like **Hilary**, work was a source of routine and direction during the uncertain months of lockdown:

“Work was good for me and kept me going. Easter was probably one of the hardest times for me because I was off work for so long...Whilst work is a source of stress, it does give me a purpose and I think I would be feeling a lot worse without it.”



Hilary here is expressing a common feeling: that work gives us a sense of purpose, which is positive for anyone’s wellbeing. But our stories draw out just how important this can be when our lives and identities are interrupted by illness. When **Penny**’s (51; auto-immune conditions, anxiety) clients started to return after the first lockdown, she was glad – despite her substantial health challenges – ‘to feel useful again’.

Employers who support people with LTCs to join and remain in work will find a committed and enthusiastic workforce with skills to contribute.

### 3. Part-time work is a key part of the solution for helping people with LTCs remain in work

Around one in three disabled workers work part-time, compared to one in four non-disabled workers.<sup>6</sup> Older workers with health conditions are four percentage points more likely to want to work fewer hours than those without.<sup>7</sup> Many of our participants spoke about finding ways to work more flexibly – including part-time contracts, zero-hours contracts, and self-employment – so they could match their work to their energy levels.

As **Penny**, who worked three part-time roles at the start of the pandemic, put it:

“When you get that fatigued it takes a long time to get back, which is why I have the jobs that I can come in and out of.... More part-time work, that’s always been my sort of saviour because not being well, a full-time job sometimes you’re not well enough to do that, whereas a part-time job you can be reliable.”



When Penny’s work dried up during lockdown, the lack of part-time work available elsewhere was a real problem.

**Julia** (51), a bar supervisor living with several physical and mental health conditions, also valued the flexibility of her zero-hours contract role:



“I only work on [specific] days or a few odd days when other stuff is going on, so if I wasn’t feeling well I could just say no.”

Part-time jobs offer the flexibility needed by people who can’t work for long stretches. They offer a way for employers to make the most of the skills of people who can’t work full time. Zero-hours contracts can be beneficial for those who need to flex their hours to match their energy levels.

Clearly, however, these benefits do not mean that workers with LTCs are not vulnerable to the same disadvantages faced by all workers on ‘atypical’ contracts. For example, recent research has shown that around a third of people on zero-hour contracts do not qualify for Statutory Sick Pay (SSP) at all – as they are less likely to meet the lower earnings threshold.<sup>8</sup> The ‘asymmetry’ of zero-hours contracts means that not all workers are as able, as Julia is, to say ‘no’ to shifts. All part-time work of course carries with it an income penalty – and with it a reduced ability to save for a pension. They are one of the key constituent groups for whom ‘pensions adequacy’ (see forthcoming Ageing Better report) need to be considered.

Some of our participants actively chose zero-hours contracts, but that is not really a choice at all if they were driven to it by the inaccessibility of most employment. More genuine flexibility in more traditional employment contracts has to be part of the long-term solution to supporting more people to remain in work.

#### 4. Stigma – from age and disability – prevents many older workers from disclosing their LTC to their employer

Participants with complex mental health conditions or ‘invisible’ physical conditions were more likely to report experiencing stigma. **Susan**, who lives with chronic fatigue syndrome, said:



“If people meet me, they meet this very gregarious, very outgoing, capable woman. If I said to somebody I’m coming for this job but I suffer from chronic fatigue...you just worry they’re going to think you’re actually just a bit flaky and a bit lazy.”

Some participants felt that their employer lacked awareness and understanding of their condition, which meant they were not able to access the support they required. **Peter** (51; bipolar disorder, kidney disease) only partially disclosed his condition:



“I have just told them I have depression. I did not disclose the full extent of the bipolar disorder as I thought that it would be detrimental to my application. Employers understand depression, whereas they may not understand bipolar...there is still stigma there.”

There were some participants who did not disclose their condition to their employer, even though they thought their employer would be supportive.<sup>9</sup> **Mary** thought her employer would ‘bend over backwards’ for her, but had chosen not to disclose her Parkinson’s disease:



“I really enjoy my role...I will disclose my condition when I feel that I can’t do my job sufficiently well, but at the moment I am still very capable of doing my job. I just don’t want to have the disability label.”

In these cases the participants seemed to be coping well – not disclosing their condition to their employer did not seem to be detrimental to their working lives. But it speaks to an internalised ableism, which in turn highlights that we have some way to go before the experience of LTCs in the workplace is normalised.

These participants who were worried about appearing ‘vulnerable’ to their employers clearly demonstrate, through their stories, that they are not. It is up to employers – and wider society – to proactively create a culture where disability and LTCs are proactively discussed and not automatically associated with vulnerability and sympathy.

## 5. All workers need access to decent sick pay

Two of our participants had experienced an extended period of sick leave, due to cancer – **Emma** (63) and **Karen** (64) – and had been paid fully by their employers during this time.

Both spoke about the positive impact it had on them. Emma said her employer was ‘fantastic. They said don’t worry about your job or income, just concentrate on getting better.’ Karen said, ‘The stress relief to still have the income all this time is beyond description.’ A third participant – **Amelia** (53) – received a cancer diagnosis during our research period. As a civil servant, she has

access to good sickness absence pay, so she does not have to worry about finances.

Other participants in our study were struggling financially – although not due to a lack of sick pay. But the pandemic has brought into sharp focus how low the rate of Statutory Sick Pay (SSP) is in the UK. This may have contributed to ‘presenteeism’ among some of our participants – working when they really were not well enough to – with detrimental implications for their long-term health. Survey evidence suggests that presenteeism was on the rise prior to the pandemic: 89% of employers surveyed by CIPD at the end of 2019 said that they had observed presenteeism in the previous 12 months, compared with 72% in 2016.<sup>10</sup> The drivers of this increase are unclear: previous research found that changes to sick pay has a significant impact on rates of absenteeism (and so, presumably, presenteeism) – but workplace culture and job (in)security are also key factors.<sup>11</sup>

For many years, the UK has had the lowest rate of mandatory sickness pay in the developed world. In the OECD, only the United States and South Korea have a lower replacement rate compared to previous earnings than the UK. In both countries, there is no mandatory sick pay at all. The UK’s replacement rate is less than 10%, compared to an OECD average of over 60%.<sup>12</sup> It is true that most people receive some form of sick pay from their employer, but just over a quarter rely on SSP alone, and they are overwhelmingly concentrated in the lowest paying industries.<sup>13</sup> People who are earning an average of less than £120 per week are entitled to no SSP at all, including 25% of workers over 65.<sup>14</sup>

There is little financial support for self-employed workers who are not able to work through illness. This is particularly relevant

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to the 50–70 age-cohort – as rates of self-employment rise with age. During the pandemic, most countries expanded sick pay to include the self-employed. Instead, the UK lowered the minimum income floor for Universal Credit assistance. The self-employed can either apply for Employment Support Allowance, which pays £20 less per week than SSP,<sup>16</sup> or Universal Credit, for which there is a five week wait for the first payment. Neither of these options provide an immediate safety net for self-employed people who are not able to work through illness or disability.

All workers should be able to experience the security that Emma, Karen and Amelia felt. Removing the earnings threshold – extending sick pay to those earning less than £120 a week – would extend eligibility to around 1.9 million people, according to figures from the TUC.<sup>17</sup> Increasing the rate of SSP – bringing it in line with the European average – would protect the health of workers with LTCs, ultimately prolonging their participation in the workforce.

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### 6. Older workers with LTCs worry about ageism as well as ableism

Participants expressed concerns about discrimination based on age as much as on the basis of their condition. Like the participants in our previous study looking at age-bias in recruitment, **Kate** (62; depression, anxiety) felt that she was overlooked by recruiters because of her age:



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“People don’t really want to employ 62-year-olds...when you send a CV off you don’t have to put your age anymore and they’re keen...and then they’ll ring you up and ask you how old you are and it’ll be they’ll get back to you and they don’t.”

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**Caroline** was in a particularly toxic environment where she felt singled out due to her age and her lack of familiarity with certain technologies:



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“I have received some snide comments from some of the younger members of staff. ... An age issue does come in. I find the technology much harder, and when your manager sends a message to the team saying ‘OMG, it’s like teaching my mother’, instead of providing [the] right support, it’s difficult.”

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Recent research has highlighted that ageism – when directed at older people – is in part ‘hidden ableism’, based on an assumption of impaired capacity as we age.<sup>18</sup> Kate and Caroline certainly felt that their age added an extra layer of potential disadvantage in the way they were treated, on top of their LTC. Creating an age-inclusive culture – where older workers are vocally valued and actively recruited – is as important for older workers with LTCs as for all older workers.



## What has changed over the past year?

### Employers who provided good support prior to COVID-19 commonly continued that practice during the pandemic

Our participants reported varied levels of support and understanding from their employer, both during and after the pandemic.

Prior to starting the research, we were concerned that reduced employer capacity could lead to worsening support for workers with health conditions. Overall, however, these stories suggest that the pandemic itself did not make the decisive difference.

Employers who were supportive prior to March 2020 remained so, and vice versa. Employers who offered good support to workers with LTCs were also responsive to the wellbeing of their wider workforce during lockdown. Good employers were consistently good, and bad employers were consistently bad.

This is not a surprising finding. But it emphasises that one of the many inequalities which may have worsened during the pandemic is the gap between those who work for supportive employers, and those who do not. It also underlines the extent to which support for workers with LTCs is not a siloed issue but an expression of the wider organisational culture and priorities. Good employers might need some help identifying how precisely to best support their staff, but ‘best practice’ guidance will go ignored in the places where change is most needed.

One of our participants with poor support from her employer, **Caroline**, did in fact have an occupational health referral, but the

recommendations were not implemented. In contrast, **Henry**’s (55; depression) employer, a small organisation, did not have formal occupational health support that he could draw on. But his employer’s flexibility and willingness to rearrange his work at short notice gave him the reassurance that his condition would not cause an issue.

Overall, this finding underlines the need for a single enforcement body for worker’s rights – as recommended in the 2017 Taylor Review and promised in the upcoming Employment Bill. Poor practice in one area of workers’ rights is unlikely to be isolated from a broader culture of bad practice. But the siloed nature of inspection and enforcement means that no one body has the remit to look at practice within one employer in the round. Our research highlights that employers’ shortcomings are rarely isolated.

### Remote working was a positive change for many – but not for everyone

The large-scale move to remote working that took place in 2020 made a real difference to the lives of many of our participants. An adjustment that many disabled people previously struggled to receive has been shown to be possible on a wide scale.

For the most part, participants found the change positive. Participants like **Emma** valued the time she got back from not having to commute. **Mary**, who is living with Parkinson’s, found that the opportunities to rest made it easier to manage her insomnia. **Amanda** said she would never have considered asking her employer for this flexibility prior to the pandemic, but lockdown has shown it is possible for her to do her role from home.

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But some had a more mixed, or challenging, experience. Home working also contributed to many participants' feelings of isolation and loneliness, and in some cases made it difficult for individuals to carry out their role.

The things which made the biggest difference were frequent communication with colleagues and proper training and support to manage new ways of working. Where those were in place – as in **Amelia's** case – the challenge of managing new technologies was experienced as an opportunity to learn new skills.

More remote working will clearly open up more opportunities for people with LTCs to do roles that might previously have been unavailable to them. As one participant, **Penny**, put it:



**“If wider society embraced not just people who are older or who have health conditions, but parents who want to work part-time or carers who need flexible time, if wider society could just see that lots of people have skills that they could use... if society could just think of the world of work in a slightly different way.”**

The pandemic has shown that this can be achieved and has also highlighted some of the problems with it. Employers would be wise to learn from this great natural experiment in home working to ensure that the benefits can be properly reaped by anyone who will want to continue to work remotely in the coming years. Our flexible working toolkit offers a framework for line managers and employees to conduct clear, open conversations about future flexible working arrangements.

## The pandemic brought mental health challenges – but so will returning to ‘normal’

The impact of the pandemic on mental health is well documented: happiness and life satisfaction levels are down, and anxiety and depression have become more prevalent.<sup>19</sup>

Key workers – who continued to go out to the workplace during lockdown – have been shown to have suffered particularly high levels of stress, depression and anxiety.<sup>20</sup> **Paula** (over 50; cancer, anxiety), a participant working as an advanced nurse practitioner, reported that the complexity of cases she was dealing with during the pandemic increased, while the support she had decreased – impacting both her mental and physical health symptoms. Women and workers from ethnic minority backgrounds – particularly Black backgrounds – are disproportionately more likely to be key workers.<sup>21</sup> The fallout from this hit to mental health therefore has the potential to exacerbate existing inequalities and may necessitate substantial targeted support and investment from the NHS.

Our sample only included two people working outside the home, but it did show the toll that remote working has taken on many. The isolated nature of remote working means that signs of deteriorating mental health may not be picked up as they would have been before, and avenues for discussion around mental health may be smaller.

Many of our participants reported worsening mental health over the course of the pandemic. **Kate's** anxiety and depression worsened, but she largely attempted to manage this by herself. She was hesitant to contact the GP because of a sense that the NHS was ‘overwhelmed’. Clearly, the underlying demand for mental health services

has risen but may not be visible if people are choosing to stay away from help.

Lockdown itself increased many of our participants' sense of isolation. But emerging from lockdown, and returning to the workplace after a period of absence, is also a source of anxiety. Employers need to be mindful of the stress this will bring to some. Services accessed via the GP will be crucial, but so will occupational health support for mental illnesses (as distinct from 'mental wellbeing' support to help clinically mentally healthy workers manage stress preventatively).

### Jobseekers with LTCs were worried about the rise of ageism and ableism in a competitive job market

As described above, our participants were worried about and had experienced ageism in the workplace. These concerns were particularly acute among those who now faced looking for new work, like **Julia**:



“I think it's very hard to get a job at the minute. Especially as I'm not a young kid that's fit and can just do anything...it limits me for what I can apply for...and I just think there are going to be a lot of people better qualified than me.”

People with disabilities are already eligible for more intensive employment support via the Work and Health programme. But it is not clear that all of our participants would fall into that category. People age 50+ are not automatically eligible for this extra support, even though their outcomes on the Work Programme (which preceded the Work and Health programme) were worse than any other

group. Our participants always described fears of discrimination in relation to their age, never purely in relation to their health.

Under the government's Plan for Jobs, designed to support jobseekers in this new recession, we need targeted tailored support for older jobseekers, designed to build on their assets. And we need a clear message that employment discrimination on the basis of age is never acceptable.

### Shielding letters provided certainty and clarity for some vulnerable workers and their employers

At the start of the pandemic, several of our participants were sent an official government letter telling them to 'shield' – to remain inside their homes, due to their extreme clinical vulnerability to COVID-19.

The shielding letter operated as a tool to support their request to their employers to work remotely. As **Ben** (56), someone in the building trade living with Crohn's disease, put it:



“He couldn't really argue with it could he. It was an official letter from the government telling me to shield.”

The letter was decisive for **Caroline**, whose line manager originally did not want to permit her to work remotely.

**Paula** was originally asked to shield, but then (after 8 weeks) told she did not need to and returned to her frontline work in healthcare. This change was unsettling – as shielding status had made her feel secure and protected. The National Audit Office investigation into the

## Findings

government's support for clinically extremely vulnerable people found that the 'iterative' development of the shielding list led to confusion, as did a lack of communication the Department of Health and Social Care (DHSC) public health bodies and GPs over the status of individuals.<sup>22</sup> While the letter provided clarity to Ben and Caroline, this was not a universal experience.

'Shielding' as a category was removed in April 2021, as infection rates fell and most shielders had received their first vaccination dose. But we remain in a changing situation. As new variants potentially emerge, some people with these conditions may once again feel vulnerable and wish to work from home. The government should not delay in reinstating this category if vaccine-resistant strains start to spread – obliging employers to allow their vulnerable workers to protect themselves.

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### **The pandemic has given many older workers an opportunity to reflect on their future**

The COVID-19 pandemic provided participants an opportunity to reflect on what is important to them and what they want from their lives. For many participants it encouraged them to reassess the quality of their life and consider how they can spend more time doing things that they value.

This period enabled participants to consider the role that they wanted work to play in their

life, particularly in relation to their health condition and thinking about how long they may be in their role or what they would do if their condition worsened. For some, the pandemic had made them consider their retirement plans, with several participants hoping to reduce their working hours for a period before fully retiring. Participants who were not considering their retirement plans often had financial responsibilities to prioritise.

Although the pandemic did not explicitly change the retirement plans of many participants, the process of reflection had influenced participants priorities in life. The pandemic highlighted the value of work but also the importance of enjoying life to the best of your ability.

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### **Participants were resilient – and even thriving – in the face of the pandemic, if the right support was in place**

Underlying all of the stories in this research, the participants' response to the impact of COVID-19 demonstrates the perseverance and resilience they have shown in an extremely challenging situation outside of their control.

Despite significant challenges, participants were able to adapt and develop coping mechanisms in both their work and home lives, and in many cases were able to thrive in the new context. The support provided by employers, and the employment itself, was often key to this.

## Annex 1

Participant	Gender	Age	Health condition or disability	Industry	Employment status at time 2	Employment status at time 2
<b>Paula</b>	Female	Over 50	Cancer, anxiety	Healthcare	Sick leave	Working from a workplace
<b>Anna</b>	Female	51	Depression, Anxiety, Asthma	T1: Retail T2: Education	Working in a workplace	New role: in a workplace
<b>Mary</b>	Female	60	Parkinson's	Healthcare	Working from home	Working from home
<b>Amelia</b>	Female	53	Diabetes, Cancer	Civil service	Working from home	Sick leave
<b>Caroline</b>	Female	Over 60	Arthritis, Auto-immune condition, Cancer	Finance	Working from home	-
<b>Susan</b>	Female	56	Chronic Fatigue Syndrome	T1: Retail T2: Education	Employed (zero-hours) but out of work	New role: Working from home and occasionally in the workplace
<b>Lucy</b>	Female	Over 50	Cancer	Finance	Working from home	
<b>Henry</b>	Male	55	Depression	Media	New role: Working from home and occasionally in the workplace	Job ended
<b>Hilary</b>	Female	Over 50	Obesity, Back pain, Anxiety	Education	Working from home	-
<b>Amanda</b>	Female	60	Cancer, Depression	Finance	Working from home	Working from home
<b>Hannah</b>	Female	56	Anxiety, Depression, Back pain	T1: Veterinary T2: Finance	Working from home	New role: working from home
<b>Laura</b>	Female	54	Eating Disorder, Insomnia, Depression, Anxiety, Osteoporosis	Healthcare	Working from home	Working from home

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Participant	Gender	Age	Health condition or disability	Industry	Employment status at time 2	Employment status at time 2
<b>Karen</b>	Female	64	Cancer	Property	Furloughed	Furloughed
<b>Emma</b>	Female	63	Cancer, Sarcoidosis, Osteoporosis	Architecture	Furloughed	Working from home
<b>Ben</b>	Male	56	Crohn's Disease, Diabetes	Construction	Furloughed	-
<b>Jonathan</b>	Male	51	OCD, Anxiety, Depression	Finance	Furloughed	-
<b>Peter</b>	Male	51	Bipolar Disorder, Kidney disease	Education	Furloughed	Furloughed
<b>Julia</b>	Female	51	Personality Disorder, OCD Post-Traumatic Stress Disorder, Nerve condition	Hospitality	Furloughed	Employed (zero-hours) but out of work
<b>Kate</b>	Female	62	Depression, Anxiety	Hospitality	Employed but out of work	Employed but out of work
<b>Penny</b>	Female	51	Auto-immune conditions, Anxiety	Events	Employed (zero-hours) but out of work	Employed (zero-hours) but out of work

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