Centre for Ageing Better

The impact of COVID-19 on older workers with long-term health conditions

Lived experience case studies

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in partnership with:

ies institute for employment studies

About us

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.

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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Executive summary

Background

Prior to COVID-19, an employment gap between those aged over and under 50 already existed. This disparity has been exacerbated by the pandemic, as **older workers have been amongst the worst affected in terms of furlough and loss of employment** (Centre for Ageing Better, 2020a; IFS, 2020).

Re-joining the labour market is likely to be more difficult for older workers as they face additional barriers in comparison to their younger counterparts. Older workers are more likely to have a long-term health condition (LTC; ONS, 2020a) that causes disability, and therefore are more likely to face ableism and ageism in the employment process (Van der Horst and Vickerstaff 2021).

The Centre for Ageing Better (Ageing Better) predicted that the COVID-19 pandemic could create additional risks for older workers who live with a LTC, such as reducing employer capacity to provide reasonable adjustments for those with health conditions, limiting access to treatment that may lead to worsening conditions, and reducing priority for older workers to receive employment support. On the other hand, **changes to work because of the pandemic could benefit how this population are able to manage their condition** through greater flexibility and home-working.

Ageing Better wanted to understand how these dynamics would materialise in reality and ensure that their response to these issues is informed by lived experience. To understand how the pandemic affected the employment experiences of those aged 50 and over who live with an LTC, research was undertaken by the Institute for Employment Studies (IES) to explore individuals' working experiences before and during the pandemic, as well as their views on the future.

To explore how experiences changed over time, participants were invited to take part in two interviews: the first in August or September 2020, and the second in February 2021. Participants also took part in a prompted online journaling exercise between the interviews.

Key findings

Thematic analysis of the interviews and journals found a large variety in how the pandemic had affected participants based on their employment contract, health condition, and support received. However, despite these differences, several common themes were identified.

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

Participants reported varied levels of support and understanding from their employer, both during and after the pandemic. Some employers were perceived to offer valuable support in response to a disclosure or issue relating to an LTC, but there was little evidence of employers offering adjustments or support aimed at preventing health conditions. Overall, the pandemic itself did not make a decisive difference to the support offered by employers: those who were supportive prior to the pandemic remained so, and vice versa. While the type of support did not change, the levels required were increased because of the pandemic, and more people needed support.

The provision of specialist equipment was one of the most common 'reasonable adjustments' supplied to participants. However, participants reported most valuing flexibility in working hours and emotional support from their employers.

Where emotional support from employers was lacking, it posed a problem for participants during the pandemic, because of the changes that took place in people's work and personal lives. In some cases, this lack of support contributed to the exacerbation of participants' LTCs.

> **"They should have recognised I wasn't coping – there were days I burst into tears on more than one occasion. A regular chat, if that did happen, it may have been spotted earlier – could have helped prevent it."** Paula – working in a workplace and living with a physical and mental health condition

2. Remote working was a positive change for many, but not for everyone

Most participants had worked from home for some period during the pandemic, which had both positive and negative consequences.

Remote working enabled many participants to better manage their LTC because of the greater time and flexibility working from home afforded. For many participants, flexible, part-time, or home-working offered the support to enable them to continue working. It also offered the opportunity for some participants to learn new skills and ways of working. Following the large-scale shift to home-working that has taken place as a result of COVID-19, participants felt that there was increasingly greater acceptance of these ways of working by society.

However, 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.

> **"I am enjoying the opportunity to have greater freedom and flexibility and so can make sure I look after myself better by pacing myself and trying to take regular gentle walks when I am feeling strong enough…It's a real double-edged sword, it's fantastic that I can work from home, however because of it [working from home] in this new role I haven't felt that I've become part of the team."** Susan – working from home and living with a physical health condition

3. Participants were worried about the impact of ageism and ableism on their ability to return to work, in the context of a more competitive labour market

Of those participants who were out of work or were furloughed, some were considering looking for work elsewhere. However, their experiences of ageism, and fears of employers' ableist views, made them apprehensive about how they would fare in the labour market. These concerns were heightened within the post-COVID-19 labour market because it was perceived as increasingly competitive due to rising unemployment rates.

> **"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."**
> Julia – furloughed and living with a mental and physical health condition

4. Work was highly valued by participants – and not just for financial reasons

Participants commonly reported how much they valued working. This was particularly the case among those who were not working, or those who had a heightened awareness of the effect of the pandemic on other people's employment.

Employment provided participants with a purpose and for some it was also a distraction from their LTC, so they were keen to continue working.

> **"Work is really important to me, and I want to make sure that I can continue doing what I do when I can. I would ideally like to go part-time. To suddenly stop work will not be good for me, but I do realise there will come a point where I may need to step down one way or another."** Mary – working from home and living with a physical health condition

5. Stigma from age and disability prevents many older workers from disclosing their LTC to their employer

The stigma associated with LTCs was discussed by participants as one of the reasons for not disclosing their condition; with several individuals not feeling comfortable disclosing their condition to their employer. Other participants did not disclose their condition because they believed they could still carry out their job well, they wanted to avoid being labelled as vulnerable, or they did not understand what their employer could do to support them.

Participants with complex mental health conditions or 'invisible' physical conditions were more likely to report experiencing stigma. 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.

> **"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."** Peter – furloughed and living with a mental health condition

The stigma participants experienced because of their health is overlayed by their experiences of age-related stigma. This interaction contributed to participants' fears of being perceived as vulnerable or incapable and acted as an additional barrier within their current work, or in their perceived opportunities in the wider labour market.

6. With the right support in place, participants reported that they could stay in work for the longer term

Participants reported that with the right support from their employer they would be able to remain in work for the long term. Access to flexible work, and an employer who is understanding about the fluctuations of LTCs, were named as particularly important.

Thinking about what the future of their work might look like, participants also emphasised that employers needed to recognise the additional needs of older workers when implementing new technology.

> **“Provide us with the support and understand that our needs are different to the younger people… People who haven’t adapted to technology we’ll need to be acknowledged.”** Laura – working from home and living with a mental and a physical health condition

7. Participants were resilient 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.

Overall, this research shows that while the COVID-19 pandemic has had a huge impact on the lives of the participants, it has not appeared to make a decisive difference to the way in which people with LTCs experience work. The same work factors remain important: a supportive and flexible employer, and the availability of suitable work. Although the degree to which these considerations are required may have increased. Meanwhile the same barriers remain in place: ageism and ableism in the workplace, and employers without the awareness, understanding, or interest to make the adjustments their employees needed.

However, the impact of the pandemic on older workers living with LTCs makes increasing good employer practice, and preventing bad practice, all the more important. This research highlights that the issues that need to be addressed prior to the pandemic to prevent older workers from falling out of the workforce prematurely due to ill-health, are still the issues that need to be tackled.

1. Introduction

1.1 Background

Before the COVID-19 pandemic, there was already a substantial age employment gap between those aged over and under 50, with 73 per cent of people aged 50-64 employed, compared with 85 per cent of those aged 35 to 49 (ONS, 2019). The most common reason that people aged 50 to 64 give for being out of work is being 'sick, injured or disabled'; with nearly 1.2 million people giving this as their reason for being out of work in the year prior to the pandemic. Of these, one in four said they would like to be in work, and more might say the same if they felt there was suitable work available (The Centre for Ageing Better, 2020a). While older age does not guarantee the presence of a health condition, age and health do intersect as older workers are more likely to be living with a long-term health condition (LTC); 45 per cent of those aged 50 – 64 report at least one LTC, compared to 28 per cent of those aged 30 to 49 and 23 per cent of those aged 16 to 29. The most prevalent LTCs for those aged 50 – 64 are diabetes (39 per cent), cardiovascular issues (36 per cent) and musculoskeletal back or neck problems (36 per cent) (ONS, 2020a).

The UK also has a disability employment gap, with those living with a LTC experiencing significant barriers when trying to gain access to and remain in the labour market (Powell, 2021). Those living with a LTC are less likely to be in work compared to the general population: in 2019, 53 per cent of disabled people in England were employed, compared with 82 per cent of non-disabled people (ONS, 2021b). However, 40 per cent of those with a health condition or disability who are not working would like to have a job, although only a third of these are actively seeking work, suggesting that job seeking behaviours are influenced by barriers to employment (Citizens Advice, 2017).

In addition to barriers accessing employment, disabled people are also twice as likely to fall out of the labour market (Citizens Advice, 2016) and become long term unemployed (Citizens Advice, 2017). Evidence suggests that barriers to remain in employment include the experience of stigma, difficulties in disclosure, and variable employer support (The Centre for Ageing Better, 2018). Fears of being negatively perceived, concerns about job security, and the associated stress of disclosure because of stigma, can prevent individuals from discussing their LTC with their employer. This leads to many employees clinging on to their work without support for as long as they can, until employment is no longer feasible. For individuals who do disclose, the level, type, and duration of the support offered varies, and is not always implemented in an effective, adaptive, or sustainable way which helps the individual to remain in employment long-term.

These age and health inequalities have been exacerbated over the course of the COVID-19 pandemic, as older workers are some of the worst affected. During the first lockdown in March 2020, the proportion of those aged 50 and over who claimed unemployment-related benefits nearly doubled, and one in four furloughed workers during the first lockdown were in this age category (Centre for Ageing Better, 2020a). Of self-employed workers aged 54 and over, only one in five reported they could continue working as normal, and a third were not working at all (IFS, 2020). Older workers who fell out of employment due to the pandemic face additional barriers to regain work and are nearly twice as likely as younger workers to face long-term unemployment (Centre for Ageing Better, 2020a). Furthermore, disabled workers were more likely to be made redundant during the pandemic; between July-November 2020, approximately 21 per thousand disabled employees were made redundant, compared to 13 per thousand employees who are not disabled (ONS, 2021a).

During COVID-19, some older demographic groups have been categorised as being particularly vulnerable to serious illness if they were to catch the virus due to both age and the prevalence of some long-term conditions. Multi-morbidities and complex health conditions are the likely cause of the higher proportions of those aged 50 and over who are considered extremely clinically vulnerable being advised to ‘shield’ by the government (ONS, 2020b). Prior to the pandemic, older workers with LTCs already faced significant challenges in their working lives, which have in some cases been exacerbated by the restrictions. However, the changes in working practices may also have had unexpected positive consequences for older workers with LTCs that are less widely reported.

1.2 Research purpose

The Centre for Ageing Better (Ageing Better) has a vision for everyone aged 50 or over to have access to fulfilling work, including those living with LTCs. Over recent years, better health in later life and an increase in State Pension Age has led to an extension of working lives. Over the last century life expectancy rates have steadily increased, until this trend slowed in 2011 (ONS, 2018) and health inequalities have widened (The Kings Fund, 2020). Over this time, healthy life expectancy has also increased, but not to such a significant extent. Therefore, more years are spent in poor health and older workers are more likely to experience a LTC that would benefit from an ‘age-friendly’ labour market that supports them to access and remain in work.

Prior to the pandemic, progress was being made on this agenda. The Government were considering an Employment Bill to make all jobs ‘flexible by default’, unless there is a robust business reason preventing it, shifting the onus from the employee having to request flexibility to forcing employers to offer flexibility from the first day of employment. They also consulted on a range of measures designed to support health at work, including the right to request workplace adjustments and a statutory sick pay rebate for small and medium enterprises. However, the pandemic stalled many of the proposed changes as attention was diverted to the COVID-19 response. Ageing Better identified that the risks of the pandemic on older workers with LTCs was likely to be substantial, particularly as the progress being made that would support this group had halted. These risks included:

- A reduction in employer capacity to support those with additional health requirements, from a financial, practical, and psychosocial perspective.
- Workers asked to shield may be particularly vulnerable to a deteriorating labour market, and these impacts might widen to those less clinically vulnerable, but still dealing with ill-health.
- A substantial rise in unemployment could lead to older workers and those with LTCs moving to the ‘back of the queue’ for employment support.
- Lockdown exacerbating some conditions, and reducing access to treatment, causing employment problems that may previously have been manageable.

However, lockdown and the changes in employment practices also had the potential to be beneficial for older workers with LTCs. Most significantly, the shift to working from home for many workers that may have allowed individuals to manage their condition and work more effectively. Ageing Better wanted to understand how these potential risks and benefits manifested, to ensure that their response is informed by the lived experiences of people who were directly impacted by them. Furthermore, to better support older workers with LTCs in the current context, Ageing Better sought to understand the complex ways in which COVID-19 has changed the landscape of work and health. They therefore commissioned the Institute for Employment Studies (IES) to speak with individuals who were in employment prior to lockdown in March 2020, to explore their working experiences before and during the pandemic, as well as their views on the future.

The main purpose of this research is to tell the stories of older workers with LTCs, and to illustrate the impact that COVID-19 has had, and continues to have, on their working and wider lives. It has been used to shape a set of recommendations to Government and to employers, which are published in a separate insight report. These will be used to influence Government policies and promote ‘age friendly’ employment practices. Specifically, Ageing Better wanted to explore the following research questions:

Experiences before COVID-19

- How did living with a LTC impact work?
- How are the needs of those with a LTC accommodated by employers?

Experiences during COVID-19

- How has COVID-19 impacted the work and health of people living with LTCs?
- How have employers responded?
- In what ways have the new circumstances made work harder – or easier?

Views on the future

- How do they anticipate their situation might change as things get back to ‘normal’?
- How has COVID-19 changed future plans?

1.3 Method

To investigate the research questions, 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.

- Monthly prompted online journals to capture ongoing changes and experiences as lockdown measures are eased and individuals potentially return to work.

1.3.1 Participant sample

The initial sample consisted of twenty participants aged over 50 with a range of different employment experiences and long-term conditions. In determining the sample, priority was given to stratify by the following demographic characteristics:

- current working status (e.g., working from home, furloughed)
- employment industry
- health condition
- gender.

Interview sample demographics are outlined below. It was notable that a large proportion of the sample was female, potentially because women are more likely to take part in research. Women are also more likely to live with a LTC or disability (DWP, 2021), and disabled women are more likely to be in employment than disabled men (Powell, 2021).

Table 1.1 Demographic profile of participants who participates in the first interview

Demographic		N
Gender	Male	4
	Female	16
Age	50 – 59	12
	60	5
Health condition	Physical health condition	9
	Mental health condition	3
	Physical and mental health condition	8
Current working status	Working in a workplace	1
	Working from home	8
	Furloughed	6
	Out of work (e.g. self-employed or zero-hours contract)	2
	Unemployed	1
	Other	2

Given participants were spoken to six months apart, there was some who did not participate in the second interview. Table 1.1 outlines the demographic profile of the 20 people who participated in the first interview, and Table 1.2 the profile of the 13 participants who took part in the second interview.

1.3.2 Interviews

The interviews explored participant views and experiences at two timepoints, six months apart. The first interviews were conducted in August-September 2020 and the second in February 2021. The initial interviews explored participants' experiences before the lockdown, their current situation, and what they foresee for the future. The second interviews investigated how their circumstances had changed over the past six months, and their plans for the future.

Table 1.2 Demographic profile of participants who participated in the second interview

Demographic		N
Gender	Male	2
	Female	1
Age	50-59	8
	60+	5
Health condition	Physical health condition	6
	Mental health condition	2
	Physical and mental health condition	5
Working status of main employment at time one	Working from home	4
	Furloughed	4
	Out of work (e.g. self-employed or zero-hours contract)	2
	Unemployed	1
	Other	2

1.3.3 Online journal

IES distributed a monthly prompted online journal between the two interviews. Using a simple online form, participants were asked to describe their experiences in the previous month, and how their situation has changed in relation to three research questions:

1. **In the last month, how has your work changed?**
    - Have you returned to work? Has anything changed about your role, work or responsibilities? Is anything easier or harder now? How have these changes made you feel?

2. **In the last month, how has your health changed?**
   - Has anything changed in the support you receive or the ways you manage your condition? Has your condition been better or worse? How has your health impacted your work?
3. **In the last month, how has COVID-19 and the restrictions affected you?**
   - How has it affected your health and work? How might it affect you in the coming month?

This approach captured the changing experiences of participants over time and provided an organic and participant-led narrative of how the pandemic had affected them. Overall, fifteen participants contributed to some or all of the monthly journaling.

1.4 Analysis and reporting approach

For each participant, the findings from the interviews and journals are summarised in an anonymous case study that illustrates their experiences over time. Case studies were created for all participants, even if they did not participate in all research elements; it is noted on the case study if the individual only participated in the first interview. A cross case study analysis was also conducted that reflects on the similarities and differences across time, groups of individuals with differing health conditions, or disabilities, and employment outcomes. This research does not aim to provide conclusions generalisable to all older workers with LTCs, instead it seeks to give an in-depth view of the unique experiences of the twenty participants involved in the research.

The table below lists participant demographics and employment information; where participants had more than one job, their primary role is listed. The case studies in this report are organised by participants' most recent employment status:

- working in a workplace
- working from home
- furloughed or sick leave
- not currently working.

Within these groups, case studies were organised by health condition:

- physical conditions
- mental health conditions and
- physical and mental conditions.

Table 1.3

Section	Page no.	Participant	Gender	Age	Health condition or disability	Industry	Employment status at time 2	Employment status at time 2
Working in a workplace	19	**Paula**	Female	Over 50	Cancer, anxiety	Healthcare	Sick leave	Working from a workplace
	23	**Anna**	Female	51	Depression, Anxiety, Asthma	T1: Retail T2: Education	Working in a workplace	New role: in a workplace
Working from home	26	**Mary**	Female	60	Parkinson’s	Healthcare	Working from home	Working from home
	30	**Amelia**	Female	53	Diabetes, Cancer	Civil service	Working from home	Sick leave
	33	**Caroline**	Female	Over 60	Arthritis, Auto-immune condition, Cancer	Finance	Working from home	–
	37	**Susan**	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
	42	**Lucy**	Female	Over 50	Cancer	Finance	Working from home	
	44	**Henry**	Male	55	Depression	Media	New role: Working from home and occasionally in the workplace	Job ended
	47	**Hilary**	Female	Over 50	Obesity, Back pain, Anxiety	Education	Working from home	–
	51	**Amanda**	Female	60	Cancer, Depression	Finance	Working from home	Working from home
	54	**Hannah**	Female	56	Anxiety, Depression, Back pain	T1: Veterinary T2: Finance	Working from home	New role: working from home
	58	**Laura**	Female	54	Eating Disorder, Insomnia, Depression, Anxiety, Osteoporosis	Healthcare	Working from home	Working from home

Section	Page no.	Participant	Gender	Age	Health condition or disability	Industry	Employment status at time 2	Employment status at time 2
Furlough	61	**Karen**	Female	64	Cancer	Property	Furloughed	Furloughed
	65	**Emma**	Female	63	Cancer, Sarcoidosis, Osteoporosis	Architecture	Furloughed	Working from home
	69	**Ben**	Male	56	Crohn's Disease, Diabetes	Construction	Furloughed	–
	72	**Jonathan**	Male	51	OCD, Anxiety, Depression	Finance	Furloughed	–
	76	**Peter**	Male	51	Bipolar Disorder, Kidney disease	Education	Furloughed	Furloughed
Out of work	79	**Julia**	Female	51	Personality Disorder, OCD Post-Traumatic Stress Disorder, Nerve condition	Hospitality	Furloughed	Employed (zero-hours) but out of work
	82	**Kate**	Female	62	Depression, Anxiety	Hospitality	Employed but out of work	Employed but out of work
	86	**Penny**	Female	51	Auto-immune conditions, Anxiety	Events	Employed (zero-hours) but out of work	Employed (zero-hours) but out of work

2. Case studies overview

Paula – Working in a workplace and living with a physical and mental health condition

Background

Paula is in her fifties and works as an advanced nurse practitioner, a role with high levels of clinical and decision-making responsibility, in a General Practice (GP) surgery. She was diagnosed with cancer in 2018 and underwent surgery, chemotherapy, and radiotherapy over the course of nine months; she continues to take medication to prevent its reoccurrence. Paula's illness impacts her every day, both in terms of the physical and mental trauma associated with the diagnosis and treatment, but also the ongoing anxiety about relapse. During her treatment, to manage the effect on her mental health, Paula received counselling though a local charity, and now she continues to pay for it privately.

Just six weeks after her treatment ended, Paula returned to work. Looking back on it, this was 'far too early' as she was emotionally fragile, and she felt like she had lost her resilience because she was upset more easily, and less confident in making decisions. However, she was provided with good support from her employer; she had a phased return to work where she worked reduced hours for three months, longer patient appointment times and regular clinical supervision to discuss any difficult cases. Despite the adjustments, on a bad day Paula would lack confidence in herself and feel scared, which contributed to difficulties in decision-making, or clearly articulating her thoughts. For Paula, the most helpful adjustment from her employer was the increased clinical supervision and simply the acknowledgment from her colleagues that she was not the same person as she was before her cancer. Although the support was predominantly good, it would have helped Paula to have regular meetings with her manager just to 'check in,' and find out how she was doing on a more personal level.

Impact of COVID-19

On the announcement of the March 2020 COVID-19 lockdown, Paula was initially told by the government to shield so she began working remotely. This restricted the patients she could assess, as the telephone consultations tended to be more minor complaints. While there was some online training, there was limited support from her employer on implementing these new processes, so she predominantly had to decide on an appropriate approach herself. Her employer also suggested that staff would have to 'go outside of their job remit' during this time, which Paula found stressful due to the lack of appropriate training and support.

Shielding was emotionally challenging for Paula, as the isolation was a similar experience to when she was receiving her cancer treatment. During the first lockdown, the increased clinical supervision stopped, which was difficult because Paula had found this support particularly valuable. Initially she liked working from home because it reduced her commute and she felt more relaxed as she was protected, but Paula, conscious she did not want to be perceived as 'slacking,' ended up working overtime.

After eight weeks, Paula was able to stop shielding, which she found quite unsettling because she was feeling secure and protected. There were many more safety considerations to think about, and she was nervous about forgetting them and catching COVID-19. She went back to working from the surgery and seeing patients again in the summer of 2020. Due to COVID-19, she was seeing patients who were generally a lot sicker and more complex, for which she required more clinical support. The support, however, was very intermittent. The increase in complexity and decrease in support was very stressful and potentially contributed to some further physical and mental health symptoms that Paula experienced during this time.

The additional physical symptoms got worse, which resulted in investigative tests. Paula initially continued working during these tests, but she was finding it tougher and tougher to carry on; she felt tearful and like she 'wanted to run away'. At one stage during the investigations, she was tested to see if the cancer had returned – this was 'really shocking' as she started to realise that 'she might not be okay'. It was at this point that Paula was signed off work for the ongoing investigations and related stress. Paula was also anxious about the impact of COVID-19 on these appointments:

> **"I am worried that if I have to self-isolate I will have to delay an important medical appointment. I am worried that my appointments may be delayed due to the staff in the hospital having to self-isolate."**

During her period of sick leave, Paula felt guilty for not working, but she also began to question the suitability of her job considering how stressful it had become. While she had some support from her GP and a counsellor, her employer was not in touch during this period of sickness, which she found upsetting:

> **"When I am waiting for results, I am in limbo. I didn't know if I will have to go down the cycle of treatment again… I know the potential impact on my life and also doing a job that is stressful with a large amount of responsibility for other people. It's having difficult conversations with other people when I am vulnerable myself."**

Paula's employer is considering maintaining some of the new ways of working, such as remote consultations. From a personal perspective, Paula enjoys the social element of her job and following her return to work, would not like to work in this new way permanently. Fortunately, in early 2021 all of Paula's diagnostic tests came back clear, meaning the cancer had not returned. While this has had a positive impact on her wellbeing, Paula was still questioning if her job role was right for her, considering the high level of stress, the proposed changes to patient interaction, and her ongoing medical anxiety:

> **" If I'm coming out of work stressed out of my tree, this is not good for me. Having faced the cancer and gone through chemo, almost a sense of regret if the cancer comes back, I have put myself though a load of stress here, when I could have been happier and more settled. It is more important to feel content about my work than climbing the career ladder."**

Throughout the pandemic, Paula felt her employer was mostly supportive and considered the impact of the situation on her conditions, as they made reasonable adjustments to her work. However, the emotional support and communication was lacking, and had this been present it may have prevented some of the deterioration in mental health that Paula experienced:

> **" Maybe I should have asked for more allowances, but maybe they should have recognised I wasn't coping – there were days I burst into tears on more than one occasion. A regular chat, if that did happen, it may have been spotted earlier – could have helped prevent it."**

The lack of social contact with her family, and inability to do the activities she enjoys, also became more difficult as the pandemic continued:

> **" The restrictions on local travel and activities continue to have an impact. When I'm feeling a bit low I would usually do something different to get myself out of it, go for a swim, go to the gym, go out for lunch etc."**

The future

After reflecting on her role, Paula has begun to apply for new jobs that have less responsibility and stress, but more patient interaction. She feels that this will best support her wellbeing and work-life balance. It has not been an easy decision to reach, but Paula wants to put her physical and mental health first. She is also more accepting that life is going to be different for quite a long time to come, and she cannot really plan anything. This acceptance means that she is less anxious and more settled in this way of life.

Paula's illness and COVID-19 have not changed her plans in the longer term; currently in her fifties, Paula would like to be able to consider retirement at the age of 60. Although she has not investigated it in any great depth, she is considering partial retirement while working in a low-stress nursing role. She certainly does not want to stop working yet:

> **"I enjoy working, I wouldn't want to stop working all together at the moment I would feel bored and wouldn't be productive. I wouldn't be ready to stop altogether."**

When considering her working future, flexibility is very important for Paula. Before the cancer diagnosis, she worked four days a week, often working five days' worth of hours. After her diagnosis, she did not want to work as many hours. Additionally, she thinks that it is critical that employers acknowledge that for people living with long-term health conditions some days might be better than others. Employers can be supportive by making allowances, particularly making sure people have breaks and can switch off, as flexibility and work-life balance is important to stay productive.

Anna – working in a workplace and living with a mental and physical health condition

Background

Anna, who is 51, had worked in two roles before the COVID-19 pandemic; her main employment was in retail, where she had worked part-time for the past twelve years. In 2016, Anna also started a part-time teaching apprenticeship. Anna has lived with depression and anxiety for several decades. Anna also has asthma that is well controlled with inhalers. Occasionally, it can be worse and will need steroids to manage it. The effect of the depression varies, but it can impact her sleep and cause her to be short-tempered. Anna describes the depression as a heavy feeling, and like she is unable to deal with anything or connect to other people. In the past twelve years Anna has had two periods of long-term absence from work because of her depression:

> **“On a bad day I will struggle to sleep, I might get two or three hours…I have this heavy feeling like I can’t deal with anyone or anything…I’m at home and have to get the kids up and that can be really hard, I’ll snap at them and then I’ll feel guilty…I won’t feel connected to anyone or anything…I just hope that tomorrow will be a better day.”**

For some time, Anna took antidepressants sporadically, but five years ago she decided to go on a long-term medication. This decision was difficult for Anna to accept initially as she saw it as a failure, however she was also relieved because it has helped manage the fluctuations in her mental health. To help manage her condition, Anna also meditates to help her sleep and tries to exercise:

> **“The depression is very up and down…I find I go on anti-depressants and they work after six months to a year, and so I come off of them and will be fine for a while, but then the cycle starts again.”**

Anna has a child with a health condition, and the extra caring responsibility can negatively impact her mental health. However, she has a good support network she can draw on when she is not feeling well. She particularly values the support from friends with similar lived experiences:

> **“I talk to my friends who have the same problems and I think ‘why can’t I cope’…but I know I need to not be so hard on myself…it all comes down to chemical imbalance.”**

Anna has found both her employers to be very supportive, particularly when she has needed to go on long-term sick leave. Her managers would call and check in with her to see how she was doing, not to pressure her to return to work.

When returning to her retail role after a period of sick leave, Anna used her employer's occupational health programme. They gave advice, put a plan in place for her return to work and followed up with her. Initially, Anna worked shorter shifts and had additional breaks to help her adjust. Anna was reassured that she would not be judged by her employer or colleagues when she returned; she was confident no one thought it was her fault and they just wanted to help her:

> **"The checkouts can be overwhelming but I knew that anytime I needed to go off I could just ring and someone would come and take me off so I could go off the floor for 5 minutes."**

Impact of COVID-19

Before the first lockdown, Anna's anxiety began to worsen, particularly because of her child's increased health risks. She removed her child from school, but also felt anxious for herself going to work. The school where Anna was completing her apprenticeship shut completely so she did not have to attend work there. In Anna's retail role, she spoke to her employer about the possibility of moving to a back-office role; but as this was not possible, and after speaking to her GP and occupational health, she was signed off from work with anxiety.

At first, Anna thought the lockdown would only last a few weeks and she got in a destructive routine of staying up late, watching too much of the news and staying in bed. Once she realised the circumstances were going to be more long-term, s he knew she needed to 'pull herself together'. Her GP offered to increase her medication, but she decided she would rather see if she could cope without an increase. Although Anna was not asked to shield personally, she did so voluntarily on advice from her child's doctor. Initially the extra precautions made her anxiety worse, but over time it became normal for Anna. At lockdown progressed, she started to go out more and recognised that exercise was good for her mental health.

In May 2020, Anna returned to working at the school, which she was happy to do as appropriate social distancing measures were in place. At the beginning of July 2020, Anna also returned to work in her retail role. This was more difficult because some of the restrictions had been lifted, and Anna felt that customers were 'not taking it seriously anymore' which concerned her. Her manager continued to be supportive, and her employer told all employees they could remove themselves from the shop floor if a customer was being irresponsible. This reassured Anna, and after a few shifts her anxiety improved. In August 2020, Anna left her retail role to start working full-time at the school as a teacher. She is now working five days a week part time, due to caring responsibilities.

The increase in hours and more regular schedule than shift work helps Anna keep a better routine which benefits her health:

> **"Although it isn't full time, it's nine until two or three, the hours are more and will be more regular...having two jobs my life was a bit bitty because the hours would change week to week but I should find a better routine with this new job."**

The future

In the future, Anna wants to try and better recognise when her health is deteriorating and do more to prevent a depressive episode. She will continue to manage her condition with medication and plans to try and start exercising more. Anna knows that her daughter returning to school will be a difficult adjustment for her because she remains concerned about the additional health risks:

> **"I want to try and notice when things are getting bad with my health so I can do more to prevent it, like I know my daughter going back to school will be difficult...the teachers did a Facebook live and showed us the set-up of the desks and how lunch will happen and that has made me feel a bit better."**

The lockdown period has made Anna's family closer as they have made an extra effort to do things together and she hopes they keep that up. Anna continues to find it difficult to think about 'normal' life, as it seems a long way off, but she has gotten into the pattern of lockdown life quickly and knows she will adapt again when things change.

Mary – working from home and living with a physical health condition

Background

Mary is in her early sixties and works as a trainer for a small healthcare trust; her job included occasional national travel before the pandemic. Two years ago, Mary was diagnosed with Parkinson's disease. She had been experiencing a range of symptoms for several years before the official diagnosis. Mary's main symptoms include a tremor, strength loss, insomnia, brain fog, memory lapses, and difficulties finding the right words.

> **"Getting the diagnosis was devastating…I do find myself crying every now and again, but I try to get on with things, I don't want to wallow as I know that it won't get me anywhere…Coping with it very much depends on your life attitude."**

Mary manages her condition in several ways, including a specialist exercise routine, and drawing upon her supportive partner. She also takes insomnia medication, but does not believe it works, and experiences unpleasant side effects. Before the pandemic, Mary was contacted by a specialist Parkinson's nurse, whom she hoped would be able to provide more targeted advice, but she was frustrated when COVID-19 meant that this service was disrupted. She has also found support in online communities and charities. Parkinson's UK patient charity provide a local area support officer, seminars, webinars, and online discussion forums, which Mary has found very helpful.

Mary has worked throughout her diagnosis. Although she believes that her employer would 'bend over backwards to help' and 'provide everything' she may need to make work easier for her, she has not disclosed her diagnosis to her employer.

> **"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."**

Prior to the pandemic, Mary recognised that stressful situations and anxiety can aggravate her tremors, so she tried to adjust her work and her role to reduce these occurrences. However, a high volume of work could be overwhelming and exhausting. Mary had a good relationship with her line manager and was thankful that they had regular meetings to discuss work pressures and potential adjustments to help with her fatigue.

Impact of COVID-19

With the announcement of lockdown in March 2020, Mary was told to work from home by her employer. Mary was impressed with how her employer dealt with the working from home adjustments and she was provided with all the necessary technology required to work from home, and the necessary PPE when any training could not be delivered online. Over the course of lockdown, staff were encouraged to complete a desk and screen equipment self-assessment. As a result of this assessment and following a discussion with occupational health, Mary was also provided with noise-cancelling headphones, and an ergonomic chair. At the beginning of lockdown, Mary's workload increased, which exacerbated her fatigue:

> **"Although people thought that Covid would make things quieter, things just haven't stopped for me. I've not stopped, I am exhausted. There has been a drive on staff training and learning compliance. So I am very busy."**

As Mary had not worked from home before, her work practices did require some adjustments. Initially, some training could not be delivered virtually, so Mary was travelling into work about once a week. She had little anxiety about this, as her employer was very strict about PPE provision and social distancing. Mary felt that it was important to go into work, to touch base with other colleagues and to keep her mental wellbeing in check.

> **"I think it's important for me to go in about once a week to touch base, to see people. I don't want to get out of the loop and working from home can become insular. Ideally, for me, I want to be able to go into work once a week."**

Mary missed social interaction when working from home, which led to more stress. To limit this, virtual team meetings were held at least once a week to check in with her colleagues, discuss both work and wellbeing and maintain contact with those who could help her if needed. Her line manager was also incredibly supportive and was contactable and communicative. Although Mary had not disclosed her LTC, when typing was becoming more difficult due to her LTC she was able to ask for help with specific tasks, and her employer considered adjustments to support, for example voice recognition software. However, Mary felt that more could have been done by her employer to help her adjust to the new ways of working. She reported that it was stressful 'trying to work it all out as you go along,' and that training should have been provided to ensure that they could work effectively virtually.

> **“It has become more difficult to offer the virtual training. We have received no training ourselves about the best approaches to do this. I don’t feel particularly comfortable about this as I like to be prepared.”**

Throughout lockdown, Mary had started to disclose her Parkinson’s diagnosis to some of her close family and friends, however she still did not feel ready to disclose at work, even though she knew that her manager would be supportive.

> **“At least for the time being I want to do what I can when I can, and I don’t want people at work to think that I can’t do something, and that they have to do everything for me. I still want to be thought of as [Mary], not [Mary] with Parkinson’s.”**

Mary experienced several benefits of working from home. Having flexibility and autonomy was helpful, especially when she was experiencing a period of insomnia, as she had opportunities to take breaks. Mary also thought that it was useful for her productivity, as she thought she was able to get more done at home, although admitting that she could be at risk of overworking on occasions. Although delivering virtual training was difficult, one benefit was that Mary had more control of how much of her was visible over the screen, and as such felt better able to hide her tremor.

> **“The virtual training with Parkinson’s can be better because they can only see part of you, and I don’t have to worry about people seeing my shaking or trying to hide it. I can be more careful with what I show virtually, I just wish we had the training to make it more interesting for those watching.”**

Parkinson’s was not a condition requiring shielding however she was considered highly vulnerable. Mary believed her physical health deteriorated during the lockdown. She was keen to have a face-to-face meeting with her consultant, as she found telephone consultations frustrating because some of the visual symptoms of her condition were difficult to describe.

The future

When thinking about the future, Mary explained that her medication will become less effective, but until that point, she wanted to operate as ‘normally’ as possible. Although Mary is not anxious about changes to her health in the future, she has experienced increased periods of low mood during lockdown, which aggravates the tremor. Having received the Covid vaccination through her work, Mary was hoping this would help when the lockdown restrictions were slowly removed, so she could socialise more.

When considering any implications for her future at work, Mary felt that her health would have greater implications then any changes because of the COVID-19 pandemic or her age. She recognises that her work may become more virtual in the future, but while she could, she would still like to attend the office to some degree so that she can enjoy the important social aspects of work. As a result of the deterioration of her Parkinson's, Mary has been considering her future at work, and feels that in a year's time she may consider going part-time. It would be at this point when she discloses to her employer about her health condition, with the knowledge that they would support her in any way they could.

> **"Work is really important to me, and I want to make sure that I can continue doing what I do when I can. I would ideally like to go part-time. To suddenly stop work will not be good for me, but I do realise there will come a point where I may need to step down one way or another."**

In preparation for her future, Mary has been in contact with Parkinson's UK to talk about pensions, the implications of ill-health retirement and financial information related to this. She said that the charity had been incredibly helpful in this respect and really valued the support she received. Mary believes she had a 'good employer,' both in terms of how they adapted to working from home, and the support and adjustments that they have provided. However, she would like to see employers better sign-post people of her age with LTCs to patient charities for independent advice.

Amelia – working from home and living with a physical health condition

Background

Amelia is in her early fifties and has worked in learning and development for the civil service for the past eight years. In 2014, Amelia was diagnosed with type 2 diabetes, which is managed with medication, monitoring, exercise, and diet. As well as the diabetes, Amelia has hypertension, which is managed by medication. In general, her diabetes is well managed, so it does not impact her daily life. However, when she had to travel for work, the lack of routine could impact Amelia's health:

> **"If I have to travel that can really put me on my knees…I'm not eating the food I usually would and I might go out for drinks with colleagues and stay out late at night which disrupts my routine."**

Her employer is understanding about her health conditions and allows her to take time off for appointments. The nature of her job also means she can work flexibly, which gives her time to recover if she has had a busy week travelling.

Impact of COVID-19

Initially, the lockdown did not have a big impact on Amelia's health condition. She was not asked to shield, but as a member of an ethnic minority group, who also lives with obesity and diabetes, she was aware that she was in a vulnerable group, and that catching the virus could be very serious for her. Amelia's husband is a key worker, which exacerbated her concerns, as she worried that he might catch COVID-19.

When the March 2020 lockdown was announced, Amelia's employer closed their offices, and everyone began working at home. Although Amelia was already set up to work from home, she had only done it a few times before. Some of her colleagues were redeployed, which meant her own team's capacity was reduced and Amelia's workload increased. Amelia's role also changed once working from home as she had to shift to using a virtual delivery platform, instead of face-to-face interaction. Although there have been difficulties and new things to learn, Amelia has seen it as a chance to improve her skills and knowledge:

> **"I have enjoyed the opportunity to learn new things…trying out new tools and testing new ways of working and brainstorming ideas."**

When working from home, Amelia was more conscious of her work output because she felt extra pressure to deliver. Being on her own could also be quite isolating and she found it more difficult to have productive team discussion. Her team started having 'team tea time' and daily team meetings, which were helpful in connecting with her colleagues, but she found virtual meetings exhausting.

Amelia's employer carried out a Display Screen Equipment (DSE) assessment, which ensured she had the right equipment for home-working. They introduced a wellbeing app and have an Employee Assistance Programme. However, Amelia has not accessed either as she relies mostly on her friends and family for support. Not having the daily commute has been positive for Amelia, but she has ensured that she keeps a regular structure to her day to manage her condition.

In December 2020, Amelia received a cancer diagnosis and was signed off sick. Initially, Amelia was told that she might have to wait up to two months for treatment because of COVID-19 pressures. Amelia felt overwhelmed by this prospect and was concerned about what might happen in that time. Fortunately, ten days later she was told she could have the surgery at a hospital being used for non-COVID-19 patients:

> **"At first they told me that a surgery that would be urgent usually, because the [hospital] was completely overwhelmed with Covid, so they said a surgery I would normally have within one to two weeks would be delayed for one to two months and that was really hard to hear and go through because I just thought gosh what's going to happen to the cancer mass in that time...so it was such a relief when they started to use cold sites at private hospitals."**

Amelia has undergone one round of surgery and is awaiting test results to determine the next steps of her treatment. Prior to the surgery, Amelia had to change her diabetes medication because her blood sugar levels were too high, possibly due to stress. However, since the surgery, the medication is now pulling her levels too low, so Amelia is working with her GP to closely manage her condition.

Going through this process has been difficult for Amelia because she has had to spend time in isolation, when normally she would have a lot of support from friends and family. The limitations on hospital visits meant her husband could only come with her to the door, so her time in hospital was lonely:

> **"One impact of this whole thing is just how isolating it is when you're at home...usually if you're going through something you would have a lot of support and visitors, and yes you're getting that in terms of video calls, and even people turning up on the doorstep which is lovely, but it's not the same...and it's really hard not having that contact."**

The response from Amelia's employer has been 'fantastic'. Her manager has been very supportive and empathetic towards her situation, and the organisation offers good sickness absence pay, so she does not have to worry about finances. However, Amelia is concerned about the impact on her work if she does need further treatment.

The future

In the future, Amelia plans to continue in her current role when she returns to work. She hopes the team continue to use some of the technology they have begun using during the pandemic. These ways of working have enabled events to be more accessible compared to residentials, which can exclude those with caring responsibilities and disabilities.

> **" When you do a residential it's normally a 4-day residential and that immediately shuts down people who are single parents, who have disabilities or access problems, those that can't be away from home, or carers...and we did it modular over six weeks for five to six hours on one day a week, that opened it up and made it much more accessible to people...I'd love to see that blend carry on."**

Amelia will continue to use the same approach to manage her diabetes, although she hopes to lose some more weight due to the risks of COVID-19 associated with obesity. The pandemic has allowed her to reassess what is important. Although work is important, she 'works to live,' and not the other way around. Since the cancer diagnosis, she thinks work-life balance is important as she needs to heal and does not want additional stress. The pandemic and Amelia's recent diagnosis has prompted her and her husband to start thinking about their retirement. They are both more aware of how precious life is and the importance of doing the things you want to, while you can.

Caroline[1] – working from home and living with a physical health condition

Background

Caroline is in her early sixties and has worked in a call centre for the past four years:

> **“I would describe it as a ‘young office’, and I would say that I am the oldest being at least 20-25 years. Sometimes sitting in the office with all the younger staff can make me feel like a 90 or 100 year old.”**

Caroline has several physical health conditions that have an impact on her daily role. She has been diagnosed with Rheumatoid Arthritis (RA), which causes pain in her joints. To help with the pain she receives steroid injections, which lead to side effects including hot flushes, fatigue and what she described as ‘foggy brain’, which can affect her concentration. She disclosed her RA upon joining the organisation hoping that this would lead to open conversations about workplace adjustments. Caroline also has an auto-immune condition related to her RA, which can make her eyes and throat dry, and talking to people for a long time without a break can be difficult. The condition also makes individuals more susceptible to developing lymphoma, and she has annual check-ups for this:

> **“Because of some of the side-effects it can be hard at work. I have received some snide comments from some of the younger members of staff. When my hands are sore it can be hard to work and it can take me longer to do stuff. This is embarrassing as other people in the office are so young.”**

While in her role, Caroline was also diagnosed with skin cancer, resulting in several surgeries to remove tumours. Treatment also includes a medicated cream, which leads to a skin condition that makes her self-conscious of how others may judge her appearance at work. Caroline has regular check-ups every year to ensure the cancer has not spread. Her physical health conditions have had an impact on her mental and emotional wellbeing, as she worries continuously about any changes to her body, and how this will affect how she is perceived at work:

> **“At my age, I am concerned about taking time off for cancer treatment, I am worried about losing my job. I have previously sent photos to my manager to prove how bad my skin cancer was.”**

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[1] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries.

Caroline has received some workplace adjustments, although she described having to ‘fight’ to get a workplace assessment. Caroline has a special mouse to help with her RA, and she also has a standing desk. However, because of the additional space the standing desk required, Caroline was separated from her team and colleagues who had previously been able to support her when needed. She received no additional support or further adjustment when her cancer was diagnosed.

> **“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 charity, Working with Cancer, set Caroline up with a counsellor, with whom she has discussed both emotional and employment concerns, including the legal responsibilities organisations have to employees with long-term conditions.

Impact of COVID-19

As COVID-19 began spreading, Caroline was anxious because she was vulnerable and so she started taking her own anti-bacterial gel and wipes to work to make her feel safer in the office. She kept herself up to date with government guidance and reported feeling unsafe in the office:

> **“The managers in the office were not taking this seriously enough. I kept on having to go into the office even when the government said we could work from home. I felt it would be frowned upon if I was to work from home.”**

Caroline was legally required to shield, although her manager’s response to this was not positive. Following an intervention from another manager, Caroline was sent home immediately, enforcing the correct government guidelines. The mismanagement by her own line manager created additional anxiety in an already unsettling time. Working from home required changes to her skills and job processes. Virtual learning was difficult for Caroline, and she did not get the extra training and support she requested. Although the organisation provided staff with supportive technology, it was not fit for purpose. Individual productivity was monitored, whereby low productivity when working from home could lead to a return to office working. This caused Caroline added anxiety, as she felt that she was not getting the support she would have received if working in an office environment:

> **“We got a message thanking most employees for doing a brilliant job, but that a small proportion of staff were not helping and displaying low productivity, and if that continued they would be called back to the office.”**

Team communication used mobile technology, which Caroline found difficult as her RA made typing challenging. This continued throughout lockdown and caused an enormous amount of stress:

> **“It was put on the team Whatsapp group that the manager could not help anyone else because she was ‘having to use all her time’ helping me. I felt picked on. Things are not my fault when the technology doesn’t work. It made me feel really, really bad.”**

Caroline was concerned that this added anxiety was having an impact on her health condition and led to accidental errors in her work. At times when there were staff shortages her workload was increased, and any training time was massively condensed, which made work even more difficult for Caroline. Caroline asked for an appointment with occupational health as her health conditions worsened, who conducted a workplace assessment. However, the recommendations from the assessment were not implemented. Caroline felt that her productivity reduced because she did not receive the necessary workplace adjustments. During this time, it was announced that redundancies would take place, and because of her reduced productivity, age, and health conditions, Caroline was concerned about her job security.

> **“I feel penalised for it taking me longer to do these tasks. I am even lying awake at night thinking about my work and what consequences I will have to face if I am not achieving my targets.”**

Shielding throughout the various lockdowns had a negative impact on Caroline’s wellbeing. The limited opportunities for social interaction with both family and colleagues left her feeling isolated and unsupported. The additional pain she experienced due to difficulties in accessing medical treatment also had an impact on her mental wellbeing, and she was concerned about the long-term implications of the pandemic on her mental health. Caroline continued to access her Working with Cancer counsellor, who provided useful information regarding her employment rights, signposted her to relevant external sources of help, and listened to her concerns and worries.

The future

At the beginning of lockdown Caroline wanted to continue to work from home if possible, as she had safety concerns about returning to the office and felt at reduced risk of transmission at home. However, over time Caroline found working from home harder mentally because of the lack of support, and the difficulties in using the new systems:

> **"If I had the full support I need in my job then I would be happy to work from home. At the moment I would not cope with going back to the office, as I would be anxious about catching Covid."**

However, as lockdown continued Caroline 'would return to the office in a heartbeat,' if it meant that she would keep her job and feel less pressure. The announcement of redundancies during the lockdown period added another dimension of concern. She wants to remain at work, but believes that at her organisation processes are geared towards the younger generations, making her 'stand out':

> **"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."**

With a mortgage to pay, and family to support, work is important to Caroline, but she is concerned that if made redundant, she may not find another job because of her age and long-term health conditions.

Susan – working from home and living with a physical health condition

Background

Susan is 56 years old and had been working as a part-time lead exam invigilator on a zero-hours contract for two years at the beginning of the pandemic. She typically worked 15-20 hours a week. A few years ago, following a period out of the labour market, Susan decided to look for work as she needed an income, but also wanted something to give her self-fulfilment. She has found that work has really helped her mental health as she feels part of a team, and that she is contributing to the community.

When she was initially looking for work, she found employers to be ageist, and that they would not recognise her skills. She took the invigilator role because she felt it would help her update her CV with more recent skills, such as leadership, management, and organisation. It also offered flexibility as she could pick and choose when she worked, which suited her because of her health condition:

Even though I've got all these different skills...suddenly I found myself at the age of 52, 53 looking for employment again...and I was quite shocked, I just felt everyone was a bit ageist ...trying to get a job and when you haven't got very current skills... they couldn't see past that.

Susan has had chronic fatigue syndrome (CFS) for fifteen years. She describes it as having a 'few spoonful's of energy' each day, which get used up with every task she has to do:

> **" I have to be really careful; I have what I call spoonful's of energy everyday and I can't overdo it and if I do I crash out."**

Susan describes having CFS as 'living half a life' because she is unable to do all the things she would like to do. For example, she must choose between a five-minute walk to the library or another activity, or if she socialises too much it can lead to a crash and she will be in bed for two weeks. However, she does find when things are fulfilling or make her happy, then they do not drain her energy as much. On the days she is working, she cannot do anything else, however she chooses to work as it is meaningful and supports her family financially.

When it comes to managing her condition, Susan finds the NHS 'does not know what to do with you when you have CFS', which has left her feeling disregarded. She has had blood tests, but they come back fine so she ends up having to self-manage her condition. Susan explained that CFS is usually a result of a viral infection and has found it interesting hearing about COVID-19 patients who are not recovering and are presenting all the same symptoms as her. She hoped that the prevalence of long Covid may lead to greater awareness and research into post-viral infections, which will also help employers understand such conditions.

The primary way she manages her condition is through careful management of her time and by being extremely self-aware of her limits. She goes swimming, which she describes as a 'euphoria' of exercise at the time but can lead to an excessive fatigue afterwards. She has also started doing 15-minute online yoga classes at home a couple of times a week, which makes her feel good, and is ideal because it is short.

To manage her condition alongside work, if she has an exam in the morning she will come home at lunch and do a 10-minute meditation before going back for a second exam in the afternoon. This helps her decompress and do some breathing, similar to how yoga helps. She did not tell her employer about her condition because she is worried others might perceive her as lazy:

> **"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."**

Due to the lack of understanding around CFS and some personal embarrassment of having the condition because of concerns about being perceived as lazy, Susan would rather manage it herself than involve her employer. Sometimes it is not the physical exertion but the mental energy it takes to do her job that exhausts her. However, because her work is flexible, she can ask for her work tasks to be adapted to compensate for the effects of the condition. To ensure she is not overworked, Susan will tend to underestimate how much work she wants and then asks for more if she feels well enough. Sometimes Susan questions if she would have still been appointed as lead invigilator if they had known about her condition.

Impact of COVID-19

When the first lockdown was put in place, Susan was initially out of work as no exams were taking place and she knew she would not be placed on furlough because she was on a zero-hours contract. Although she was disappointed and lost out on a lot of work, she was financially stable. As her husband started working again in May 2020 following redundancy, she was working more for herself than for an income. She decided to take up a distance learning course to gain a new skill while she was out of work. She really enjoyed doing it but could only manage about two hours a day before becoming mentally exhausted.

In September 2020, Susan started a new part-time job at the same school where she was an exam invigilator:

> **"Suddenly when you get this long-term health problem, you can't work the hours like before, you can't cope with the stress like you used to… so it was like the dream job landing in my lap, being able to engage, use my brain, but I wasn't having to do too much."**

The work is more consistent than the invigilator role, and she can manage her own workload if she meets certain deadlines. The processes in place were quite old fashioned, so she has tried to make things more digital and efficient. Working in a more virtual way is also easier for her to manage in terms of her health:

> **"I am waiting to see what will happen at the beginning of term and what effect all the necessary Covid testing will have on my role … I use Teams and arrange all meetings virtually at the moment and shall continue to do so for the foreseeable future. This is not only easier for me but it also makes it easier for [others] as there is no travel time so we are actually getting better attendance."**

Susan now works approximately ten hours a week, however it is flexible. She recently worked a 25-hour week and ended up 'crashing' because she had overdone it. The physical effect of the work can impact her mental health as she gets frustrated by not being able to do things. She currently works mostly from home, but she does attend the office about once every six weeks. She feels somewhat isolated working from home and does not feel part of the team, especially as the rest of her colleagues are working in the office.

> **"It's a real double-edged sword, it's fantastic that I can work from home, however because of it in this new role I haven't felt that I've become part of the team."**

When she has had to go to the office, she has been impressed with the school's guidance around COVID-19. The whole school is operating in bubbles, and there is a limited number of people allowed in the office, people must wear a mask when they are not at their desk and there is regular testing. The only thing that would make her working life easier would be better internet and IT support, as she has had some issues accessing servers when working remotely.

In general, Susan feels her health condition has improved since the restrictions have been in place. She was considering taking on a second role, but her recent crash has made her realise she is not quite as well as she thought, so she may not be able to cope. At first, she did not tell her new employer about her condition, however the similarities between CFS and long-Covid empowered her to tell her manager. It was not a formal disclosure and she is not sure if her manager will tell anyone else, but she felt relieved for telling him.

In October 2020, due to feeling unsupported by the NHS healthcare system, Susan decided to visit a functional medicine clinic to receive an alternative non-NHS opinion and treatment. Susan was diagnosed with adrenal fatigue and she was put on a gluten and dairy-free, low sugar diet and given supplements to take. Initially, this made her feel better but mostly it has helped her be more self-aware of her condition:

> **"I am very slowly being able to do a bit more than before – wondering whether this is diet related or due to the many supplements that I have been given. I got a bit over excited last week and overdid things and so had a few very slow, low energy days."**

She has noticed that her energy comes in two-weekly cycles of high then low energy. She continues to manage her health by walking and doing yoga as she cannot go swimming due to lockdown:

> **"I am enjoying the opportunity to have greater freedom and flexibility and so can make sure I look after myself better by pacing myself and trying to take regular gentle walks when I am feeling strong enough."**

Susan feels that the lockdown has been wonderful for her. She does not feel particularly anxious about the virus because she lives in the countryside. She thinks she would have been more scared if she lived in a city. The restrictions have allowed her to slow down and reconsider things, and it has been good for her not to have the pressure to go anywhere or do anything. She feels she has been able to adapt to lockdown life, however some family matters have made her health condition worse. Additional caring responsibilities have increased the emotional and physical demands placed on Susan.

The future

Susan hopes that the similarities between long-Covid and CFS shine a light on her condition and prompt discussion and investment in research and treatments. She hopes that people become more aware of invisible conditions such as CFS and are more sympathetic and understanding of their impact. She is also pleased that there has been a shift in attitude towards remote working and hopes this will continue going forward:

> **“I’m pleased that it’s made everyone change the way they think about working remotely... I think there will be a lot of things will be done differently going forward.”**

In the future, she had thought about taking on more work, but is not sure she could manage it now. She currently plans to take her private pension in five years and continue to work part-time to top it up, and then fully retire in ten years. She will continue to focus on slowly getting better and managing her condition in the ways she knows how: walking, yoga, swimming, and carefully managing her diary. For Susan, effective management is about having flexibility and self-awareness, and recognising that everything she does has to be in bitesize chunks.

> **“It’s given me the chance to pace myself better, so that’s actually worked in my favour.”**

Lucy[2] – working from home and living with a physical health condition

Background

Lucy has worked in the financial sector for twenty-five years and has been in her current role for just under two years. In 2017, she was diagnosed with cancer and underwent chemotherapy and radiotherapy. As a result of the treatment, Lucy now experiences fatigue, neuropathy, joint pain and lymphoedema. The fatigue is the most debilitating symptom that Lucy suffers, as it can hit her at any time without any obvious pattern. In this situation Lucy must sleep, which will interrupt her work. This can be very frustrating and affects Lucy's motivation, leaving her feeling generally fed up. Work used to involve a lot of travel, but now Lucy finds this difficult to manage and often must rely on other people to drive the long distances she struggles with. Lucy also has a young child, and her illness has negatively affected their relationship.

To help manage her conditions, Lucy takes painkillers and has recently started practicing Pilates. She used to visit the gym prior to her treatment, but she no longer feels comfortable doing this. However, Pilates has 'really helped,' as she feels more mobile and does not need to take as many painkillers. To deal with the tiredness and brain fog, Lucy 'just has to recognise when it is too much and stop and rest'. Fortunately, Lucy had the freedom to work at home prior to COVID-19, which helped as it stopped the early starts for commuting and enabled her to take longer breaks or naps. There are no questions or expectations about a return to the office from her employer, which has been the biggest benefit for Lucy.

Other than providing the option to work from home, Lucy's employer has not been very supportive. When she was first diagnosed, her line manager made inappropriate comments based on their lived experience of cancer and 'hounded' her with phone calls. This resulted in a change in line management, which was positive for Lucy as her new line manager listened to her. During her sick leave, Lucy was made redundant. She challenged this decision and was eventually offered a more junior role. Since her return to work after her sick leave, Lucy has had multiple line managers of varying quality. As well as the poor quality of some managers, the constant churn is frustrating as she must inform each new manager of her situation. Overall, the impact of the cancer and the treatment has been substantial for Lucy, even on a 'good day' she cannot perform to the same level as she did before:

> **" Even on a good day I'm not the person I was before I was ill."**

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[2] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries. The participant was not able to discuss their future, so this section has been removed from this case study.

Impact of COVID-19

As Lucy was already working from home prior to COVID-19, the shift to remote working did not change anything as far as her working set-up was concerned, and therefore the impact of the pandemic was less significant for her. The organisation expedited the use of virtual platforms and attempted to create a team atmosphere; she feels that she sees her team 'more now than ever.' However, work became busier during this time and her organisation went through multiple changes.

With a young child, Lucy also had childcare pressures to contend with, which meant she was unable to nap during the day if needed. Although her employer outwardly acknowledged the additional challenges employees faced, she did not feel she received the same level of flexibility as other colleagues. Lucy felt frustrated and disappointed as she believed that employer practices were being applied inconsistently. Fortunately, her work level has returned to normal following a peak at the start of lockdown, which means she has more structure and a better work life balance. Her child being able to return to school 'took a massive pressure off' as it provided them both with more structure and routine. The ability to take a longer period off over the Christmas break also helped Lucy rest and recharge:

> **"I was constantly tired which made motivation difficult. I used the time off over xmas to recharge and focus and came back in the New Year to successfully securing a new role which I start in a few weeks. I think since returning after xmas my workload has been more stable and I have been slightly less tired so think I have been able to manage work more effectively."**

The lack of access to exercise classes has also been very difficult for Lucy during the various lockdowns, especially as it is one of the ways she manages the physical side of her health conditions. This has meant she has felt more physical pain during this time:

> **"I have missed not going to the gym for Pilates classes which really help my mobility. I had previously not been swimming, although that also helps, but unfortunately just as I had started again we were locked down again so [have been] unable to swim."**

Henry – working from home and living with a mental health condition

Background

Henry is 56 years old, and before the pandemic worked in a part-time financial role in the media industry for six years and did some freelance finance and administration work. He is also undertaking a university degree. Henry has been living with depression for about fifteen years. He takes medication to treat his condition although does not like using it for long periods of time, as he finds it more effective after a break. He regularly visits his GP for a check-in and has also had therapy in the past. Exercise relieves stress and lifts his mood, and he likes to read to distract himself from his depression. As Henry had recently started a degree, he has also received additional support from the university's mental health services.

The impact of the depression varies day-to-day, and he finds the symptoms materialise without any obvious catalyst. He usually copes by just 'riding through it', with the knowledge he will feel better the next day after he has had some sleep. His depression can affect his close relationships and his activity levels; simple tasks such as cleaning his house can seem overwhelming, so he must break things up into smaller tasks:

> **"It is up and down...sometimes not for any particular reason, sometimes I just wake up and have a day where I feel really down about stuff for no reason, but I know probably after sleep I'll be better the next day."**

The apathy he experiences has the biggest impact on his work as it stops him from getting anything done. However, his employer is very flexible around his working pattern, so if he cannot work on a certain day due to his condition then he can rearrange at very short notice. They are very understanding, and it is reassuring for Henry to know his condition will not cause an issue at work. There are not any formal support services, such as occupational health that he can draw on, however he would not expect them because it is a small organisation. His self-employed work also offers flexibility, and part-time working suits him more than a regular full-time job:

> **"Because of my depression sometimes I just didn't feel up to it, but fortunately the people I work with were very helpful...[his employer] was very flexible about what days and times I came in... if I needed a day off or needed to change days and times round they were always pretty good with that, so that was nice to know."**

Impact of COVID-19

At the beginning of the first lockdown, Henry felt isolated as he lives alone. Initially, Henry started working from home, which he did not mind at first as it gave him even more flexibility, however there were some IT issues with setting up remote working. He did find when his mood was lower it was easier to put off working because he was in a home environment and there was no one else around working.

After a few months, he ended up working back in the office because they were given the option and he found having the structure to his day made him more motivated. He was comfortable returning to the office as there was plenty of space. The one colleague he did work closely with was still working from home, so it was easy to social distance. There were also new cleaning procedures such as hand sanitiser, sprays and having to wipe things down after use. However, in August his part-time work came to an end, and his self-employed work dried up over time:

> **“Work has changed because of the Tier 4 situation – a lot of the people I do work for are not able to work at the moment, so this impacts my ability to work. It is worrying that the restrictions on people working are causing lots of problems – quite severe financial problems in my case.”**

He has had to deal with having a reduced income which is very stressful, and he missed out on receiving a government support grant because of his previous part-time employment status. He emphasised his frustrations with the restrictions the government have put in place and how unfair he felt these were for self-employed people. He has been looking for some part-time work but feels the labour market is really deflated and employers are not taking on casual staff because of restrictions and social distancing.

To maintain social contact a group of friends set up a regular video call. He has also been able to create a support bubble with a friend who lives locally, which has been beneficial for him. As the lockdowns and restrictions have continued, he has begun to feel increasingly disassociated from other people, and that in turn makes him want to have less social interaction.

Throughout the pandemic Henry has been speaking to his GP less often and via an online consultation, but he is reassured that if he needs to, he will always be able to talk to her about his health. He spoke to his GP early in the first lockdown about increasing his medication because his condition was worsening, and he has found this helped him:

> **“My depression is getting worse and this is affecting my motivation. I am struggling at times to cope with everyday tasks.”**

However, in December 2020 he chose to stop the medication altogether as he wanted to try and deal with the causes of his depression himself rather than treat the symptoms:

> **"I got to the stage when I was feeling really down using it [medication], hopeless and like I've got no control over anything…those sort of anti-depressant medications are just dealing with the symptoms, they aren't dealing with the causes…just trying to take control of things a bit more."**

Since then, he has had some bad days but generally feels he has been more positive. He has tried to take more control over his life and do more exercise to manage his condition. The depression does still affect his motivation some days, particularly to do household chores because he is on his own.

The future

Henry hopes that as the restrictions are relaxed his clients will go back to work and his self-employed work will increase. Although he finds it difficult to see how and when things will change. He is trying to see the loss of his work positively, as he has his university course and as it is his final year it will be important to have the extra time to study.

> **"Everything's getting affected at the minute… you don't know how the rules are going to affect whatever you want to do, because you don't know how the Government is going to implement them and also how other organisations might implement them…so it's too hard to say at the minute."**

In terms of his health, he wants to continue to take more responsibility for it himself. In part, because there is reduced access to health services at the moment, but also because he does not want to burden them. He will continue to exercise as that improves his mood and helps with stress relief. He does not have solid future plans as he feels there is a lot of uncertainty. The rules affect everything, so Henry finds it is difficult to make plans for the future. He is looking forward to things going back to normal and has learnt the importance of valuing his friends and family and the things that matter, and putting less faith in the government to look after you.

Hilary[3] – working from home and living with a physical and mental health condition

Background

Hilary has worked at a university for the last six years and has lived with obesity for most of her life. She also has a back injury following an accident. Due to living with obesity, standing was incredibly difficult and so the injury took longer to heal. Hilary also lives with depression that she thinks is related to her weight. Nearly two years ago she had weight loss surgery which had a positive impact on her health and wellbeing:

> **“Before surgery my weight had an impact on my work and socially. It was just impossible to arrange to do anything when you could barely walk 100 metres.”**

The surgery was a turning point and has radically improved what she is able to do both physically and socially. In addition to the surgery, Hilary has also started a course that looks at the compulsive and psychological side of over-eating and obesity, which she hopes will also help her manage her weight-loss. Her employer has been supportive both before and after her surgery. Simple adaptations such as being allowed to sit whilst delivering presentations, having a parking permit, and having a special chair were all examples of the help her employer provided. However, before weight-loss surgery the social side of work was more difficult because of her depression, although this has improved since surgery:

> **“They did used to have social activities but [I] didn’t take part because I would have been exhausted carrying the extra weight around, or they would go to a restaurant and it may have had fixed seating where I wouldn’t fit, so was embarrassed about going out with them.”**

Before lockdown Hilary was feeling well, although she was experiencing anxiety. Hilary took an ‘open approach’ to issues at work and found that her work colleagues were generally very supportive if there was anything she was particularly anxious about. Her line manager was very open and allowed for time off for appointments when necessary. Hilary also had an occupational health assessment. Her current role is less stressful and competitive, which ‘suited her at this time of her life’:

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[3] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries.

> **“I don’t think there is much more they could have done for me. If I needed anything, and I asked for it, and it was reasonable, then I would get it.”**

Impact of COVID-19

In March 2020, Hilary’s employer recommended working from home before the official government lockdown was introduced, with only essential workers needing to attend the office. Hilary found the first few months of lockdown emotionally difficult. In the first three weeks she put on weight as she was moving less than usual, and her anxiety meant that she was eating for comfort. She arranged a virtual appointment with a dietician and has since lost this weight. The social isolation because of living alone in lockdown really affected Hilary, and although she was using virtual technology for catchups, this was by no means an acceptable replacement for ‘real conversations.’ Her anxiety was keeping her awake, and she was beginning to think that she could not cope. GP appointments and dietician appointments also became virtual, further reducing social contact. The uncertainty of the situation was consuming, and as the lockdown went on the depression then crept in:

> **“The problem with lockdown was before the surgery and losing all the weight I felt like a prisoner, and I felt like a prisoner again in lockdown. I felt like I was back in that terrible space again.”**

Once the social bubble initiative was introduced, Hilary felt a lot better because it meant that she could see her partner again, and as restrictions slowly lifted, she was able to meet with family and friends in back gardens. This really helped with her mood and her depression.

During this time Hilary’s employer had been exceptionally supportive, especially after she discussed her experience of loneliness. Hilary was invited to attend meetings so that she could interact with work colleagues, and communication changed to video calls rather than email, to provide a more personal interaction. Her employer gave staff few extra days of holiday over the Easter break as a recognition and thank you for the hard work shown throughout the lockdown. Although Hilary saw this as a kind gesture, having extra days on her own only enhanced her feelings of loneliness as she did not have her work to distract her. Following discussions with her line manager regarding a holiday that Hilary had booked, flexibility was given regarding when she could take her annual leave, so she did not have a week on her own:

> **“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.”**

Hilary recognised a few benefits to working from home, including not having to undertake a long commute every day and knowing that this was safer in terms of risks for transmission. She very rarely worked from home before the pandemic as her employer thought that they would not be able to work effectively. She also enjoys that she can work more flexibly and autonomously, and she can have more freedom over when she undertakes certain tasks. However, Hilary's back pain did flare up at the beginning of lockdown as she was not used to sitting on a hard, non-ergonomic chair, and so this was a source of discomfort. Although she was informed that she could take her adapted chair home, there were practical limitations that prevented this:

> **"My seat at home is certainly not as comfortable as the one at work, the one that they had adapted for me. That really is a decent chair and does support my back."**

Meetings in general also became easier as they did not require travel; they were quicker and easier to set up, and she felt the whole process was more effective and efficient. As training was transferred to webinars, these also became more cost-effective, and she was able to attend more as a result. To help maintain her concentration whilst working from home Hilary began to make work checklists and prioritise tasks. She missed her team but enjoyed virtual coffee mornings set up by the university.

During the second lockdown she recognised that working from home was having a negative impact on her mental health, as she was feeling more anxious, especially when the rates of transmission rose again. By early 2021, Hilary felt that she was struggling to maintain her mental health and was having trouble sleeping. Her work was busy, yet she could not concentrate on the tasks, and although her line manager was attempting to put on social events to help with team wellbeing Hilary was not motivated to attend them. However, she was pleased that she remained in employment during this time, as it provided her with some opportunity for social interaction and stopped her from 'dwelling':

> **"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."**

The future

Hilary is not sure what the future of her employment will look like and can only view things with a negative mindset. With the recognition that people can work successfully and productively at home, there has been no discussion about returning to the office. She is not currently overly fond of her home set-up, and so she hopes that at least some kind of hybrid work set-up will be encouraged, so that she could go into the office several days a week. However, she does hope that some of the virtual meetings will continue as this would significantly reduce time wasted on travel:

> **"With things as they are at the moment, I really can't imagine things going back to normal."**

She would like to continue virtual appointments with GPs and dieticians as this would mean that she could fit them in around work, once again reducing travelling times. The reduction in commuting meant that when they were open, she attended a gym, and she hoped that she could continue with this in the future.

Amanda – working from home and living with a physical and mental health condition

Background

Amanda is 60 years old and has worked in the financial services industry for the past ten years. In 2018, Amanda was diagnosed with an incurable cancer. Due the nature of the cancer, it does not currently require active treatment, instead it is monitored via quarterly blood tests. While it is currently 'stable' at some stage Amanda will need treatment to manage her condition. When she was first diagnosed, Amanda did not inform her employer immediately. When she did tell her HR department about a year later, they were very supportive. HR put her in touch with a charity support organisation, Working with Cancer, which organises monthly one-to-one support sessions – these were extended over the first lockdown in Spring 2020 to provide Amanda with additional support.

The predominant physical symptom that Amanda experiences is fatigue, however the diagnosis has had a significant impact on her mental health. She experiences periods of depression and dark thoughts, which are compounded by the stress caused by high work demands. Initially, the impact of her illness on her job role was minimal, with the occasional bout of fatigue and low mood, however this has changed somewhat over the course of the pandemic. Initially, Amanda's employer made some small adjustments for her, such as providing a permanent desk when hotdesking was introduced to help avoid germs and allowing her to work from home as soon as COVID-19 was identified as a serious concern. However, the emotional support Amanda received was minimal and this was only exacerbated by the pandemic.

Impact of COVID-19

When the first lockdown began in Spring 2020 Amanda was asked to shield, although she was already working from home. Working from home made it easier to some extent, as she did not need to worry about commuting and being as vigilant about hygiene. She expected to be in regular contact with her line manager and HR, however, this did not happen. When there was contact, the impact of her illness and COVID-19 on her wellbeing and ability to do her job was rarely discussed. Several colleagues resigned during the lockdown, resulting in additional work being given to Amanda. This was difficult to manage as Amanda did not want to use her illness 'as an excuse,' but wanted to be treated fairly considering the impact of her illness on managing very high work demands. No adjustments were made to support Amanda to manage her role and high workload.

Although the pressures of her role had increased, Amanda was glad to be working during lockdown as it provided structure while she was shielding. However, there was very little social interaction, either with her line manager or colleagues, which made it more difficult for her. Amanda would have valued both formal and informal opportunities to socialise with her colleagues. In terms of her illness, nothing really changed during the first lockdown. Her blood-tests were delayed by several months, and there were some signs that the disease was progressing, although she was still considered stable, and this did cause additional worry for Amanda. As lockdown was lifted in the summer of 2020, Amanda's employer planned for staff to return to the office if they wished, but she did not feel any pressure to do so, and was able to continue working from home:

> **"There has been no pressure to go into the office, the company has been very good. We have been provided with the equipment to work from home."**

As the pandemic progressed into early 2021, Amanda continued working from home and the contact from her line manager reduced further. Combined with the fact that organisational communication tends to happen via email, Amanda felt even more isolated. For support and social interaction, Amanda has engaged with several charities that provide coaching and 'buddying' for a finite time. This has been a great support, but it can be very difficult for Amanda when those conversations come to an end:

> **"I felt quite lost after stopping those calls. That's the problem is that the support is often for a very short period of time. When it stops it's taking the rug out from the feet."**

It became increasingly difficult for Amanda to cope with her high workload, which had physical and emotional implications:

> **"Partly from lockdown, partly from isolation, partly due to the cancer I get more tired and stressed, and I get more overwhelmed."**

Fortunately, Amanda's line manager changed during the pandemic, and the new line manager has a very different management style, which has made a positive difference:

> **"It has made a huge difference, he arranged a zoom chat rather than a call so we could actually see each other. Talked for about an hour and quarter, some of it was about work but some was not. It was on a more personal and social level.... It lifts your mood for a start, it's nice I can talk about work issues and he is listening to what I'm saying, and he is prepared to help if he can."**

Overtime, Amanda became more anxious and depressed about her health and felt less physically fit, partly because she was unable to get outside and exercise as much. Her last check-up was postponed again, and she was unable to get a GP appointment on several occasions. Although she has had her first COVID-19 vaccination, there are no guarantees of its effectiveness because of the impact of the cancer on her immune system. Some days Amanda can manage her mental health better than others; having a lot of social interaction and taking regular exercise has a beneficial impact on her wellbeing. Although she can still have very low days, she tries to keep her mind occupied, and work can help with this.

The future

Living through lockdown has shown Amanda how easy it is to work from home in her role, and this has given her the confidence to ask for more flexible working in the future. Although she would not want to work from home permanently as she feels it would be too lonely. Prior to COVID-19, she would not have even considered asking her employer for this flexibility. The pandemic has also brought the realities of her illness to the surface. The trajectory of the cancer is unknown, although she will need to have treatment in the future. Considering the incurable nature of her cancer, she questions her work-life balance and is considering early retirement, although this is dependent on her financial situation.

She would like to receive more emotional support from her employer, such as a caring line management relationship or the creation of internal networks or groups of people in similar situations. To get emotional support during the pandemic, Amanda has had to look outside of her workplace.

When thinking about the future, Amanda thinks that going back to ‘normal’ will be hard for people to adjust to and employers are going to have to take that into account. Having to mix with a lot of people will be challenging, and employers must recognise this and introduce adjustments, such as phased returns to work and fewer hours in the office:

> **“ It has been such a huge change for everyone, when it’s a matter of life or death to stay at home, having to go back is going to be hard.”**

Hannah[4] – working from home and living with a mental and physical health condition

Background

Hannah is in her late fifties and has worked in financial role in the veterinary industry for five years. Hannah lives with anxiety and depression and openly discusses her mental health conditions, as she believes it could help others disclose, and it helps her to feel more comfortable that someone is aware of her health condition if she needs help. The triggers for her mental ill-health are predominantly work-based, and when experiencing a depressive or anxious episode Hannah tends to withdraw from others and becomes overwhelmed with thoughts, which she finds difficult to order or deal with. Hannah is aware of her triggers and has introduced several mechanisms to help herself, including medication, mindfulness grounding techniques and breathing exercises when she experiences a panic attack. Hannah also experiences lower back pain, which can restrict her movement, and the pain can affect her depression.

When she started in her current role, Hannah disclosed her health conditions to her manager, and received an occupational health assessment, and desk and screen assessments. Her employer provided several physical workplace adjustments (e.g., standing desk, flexibility to walk around, ergonomic chair when needed) to aid her at work:

> **“ 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.”**

However, Hannah had experienced some mental health related stigma, especially in relation to her work capability, and she sometimes felt she had to prove to others she could do the role. The organisation had introduced measures to improve the organisational understanding of mental health, but Hannah was disappointed with the lack of overall managerial response to any suggested practices, and lack of change in wellbeing policies.

> **“ People don’t go into these things with an open mind. They see these things as a tick-box exercise instead of really understanding the issues and implementing proper policies and practices to deal with them properly.”**

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[4] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries.

Impact of COVID-19

At the beginning of the pandemic, Hannah started working from home before it was mandated by the government. She was pleased with how well organised everything was, with precautions being put in place early, including the provision of hand cleaning gels, and ensuring that the IT systems were sustainable for a full lockdown. They were also informed that if they required an extra screen or any office furniture for working from home, they would have access to this. Hannah opted to take a second screen to improve her office set-up, and although an ergonomic chair would have been helpful for her back, she did not have any room for it in her current accommodation:

> **“We were told to take laptops home in case a lockdown was called so we didn’t have to come back to the office. They had IT set up so if any issues occurred it would be sorted immediately, and video-conferencing was set up so we could contact our team and our clients.”**

The COVID-19 pandemic did have an impact on Hannah’s role. As a result of the job retention scheme, she became responsible for dealing with furlough claims, so her worked peaked at certain times of the month. The autonomy of working from home meant that on occasion Hannah would work longer hours. However, she did emphasise that it was her own choice, and she felt no pressure from her manager to do this. She has continued some tasks related to her pre-pandemic role, which she was happy to undertake, as she enjoyed interacting with her client and helping when she could:

> **“I think that I have been more productive since working from home. I don’t have other people in the office distracting me, and I feel that I can structure my own working day.”**

Hannah’s line manager checked in daily to see how she was coping and whether there was anything that she needed, which was much appreciated. To avoid social isolation, she also had daily team calls with her team. There were times when Hannah felt unable to join, and with her manager’s permission, she was told that she did not have to attend all the meetings if she was finding them difficult or mentally fatiguing.

As lockdown continued, Hannah’s team were informed they were being made redundant, because of an organisational restructure unrelated to COVID-19. This had negative implications for her anxiety, as she was concerned about the difficulty of finding a job during the pandemic, when competition for roles would be high. As the sole earner she was also worried about her financial wellbeing:

> **"It has been a real emotional rollercoaster. I was made redundant – I went into a complete panic at the thought of not having an income…My self-esteem and confidence in my work ability hit an all-time low, and I was petrified at the prospect of having to start a new role as at a new company."**

However, Hannah was able to find a new job in finance within a month. The new role was also based at home because of the ongoing lockdowns, which contributed to the anxiety she felt about starting a new role.

> **"I was relieved to have found a new job, and I am excited about starting a new job, but petrified about learning the new role virtually, and if I am actually capable. This is the usual self-doubt I often feel."**

Her new manager was very supportive and helped her settle into her new role. Hannah reported being worried about disclosing her medical conditions to her new employer virtually but was pleased that after disclosing that she received a some adjustments to make her home workspace more comfortable for her, including being provided with a supportive chair and IT equipment. This was especially important as she had been experiencing more back pain while working from home. Her line manager has been supportive of her progress, although this has not stopped anxiety about losing her job.

Hannah experienced more back and neck pain during the pandemic. However, contacting her GP during this time has been difficult, and so she had been using more over the counter pain medication. The uncertainty surrounding redundancy and job search did increase her anxiety, and there were concerns about socialising with new colleagues virtually and how this would work effectively. Although Hannah viewed some elements of the social isolation as a blessing and 'not having to feel pressurised into going out when I don't want to', being apart from family was difficult, and so a support bubble was formed when the third lockdown started in January 2021.

The future

Hannah's future plans changed due to her redundancy and new job. At the beginning of lockdown, she wanted to work in a job where she had an element of choice and flexibility about where she worked. Working from home removed some of her mental ill-health triggers, and so in the future she viewed this as a way of controlling her health. However, she did also value the support from her line manager. Hannah recognised the importance of work for her wellbeing:

> **“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.”**

With regards to the future in her new role, Hannah wants to feel more settled, which was difficult when working virtually and having not ‘met’ her new team. She is excited about a potential return to the office to meet her new colleagues face-to-face.

In terms of her health, Hannah does not like to think about how that could change in the future and admitted to burying herself in her work or something social, so that she does not have to think about it.

> **“I try to rationalise behaviours, so I ask questions like: Has it happened yet? Is it worth consuming energy in worrying about something that might not happen? Are there things that I can do to change the situation?”**

Laura – working from home and living with a mental and physical health condition

Background

Laura is in her mid-fifties and works in the health sector on a zero-hour contract. She has been living with an eating disorder, social anxiety, and insomnia for many decades; the eating disorder has also resulted in physical health conditions such as osteoporosis. Laura has chosen a role with a zero-hours contract to be able to work around her long- term conditions, as it offers her the flexibility to choose when and how much she wants to work. Prior to COVID-19, her role involved travelling and using public transport to visit her clients. This could be very difficult for Laura as it could exacerbate the symptoms of her social anxiety and eating disorder. Having lived with her health conditions for a long time, Laura knows how best to manage them using medication. Laura had not disclosed her conditions to her employer and did not want any additional support from them.

Impact of COVID-19

Following the first lockdown in March 2020, all of Laura's face-to-face client visits stopped and appointments were moved to phone calls. The amount of work reduced by about half. The impact of this was both positive and negative for Laura. The positives have been that she had to travel less, which resulted in less travel-related stress, physical exertion, and feeling less social anxiety. She has also found that her sleeping is more settled as she no longer experienced the anxiety the night before travel to visit clients. Staying at home has also meant that Laura had to make less effort with her work attire and appearance, however this could be a double-edged sword as it could also contribute to her increased apathy during this time. The new remote ways of working removed many of the barriers that Laura faced in her working day. However, working from home has also reduced her social links and daily structure which has led to her becoming more apathetic and not taking care of herself as well. Additionally, Laura also experienced a negative financial impact of the reduced workload, which resulted in her having to rely on her savings for day-to-day living. Due to her savings, she was not able to access financial support, which caused anxiety around her financial situation:

> **“My mental health has deteriorated further. I feel more apathetic and more depressed... The restrictions have caused me a mixed bag in that, sometimes I welcome the lack of social pressures, travelling for work, having to take more care of my appearance, feeling less judged etc. BUT, the trade-off is that I also feel more isolated, less part of society, easy to get into a negative spiral mood wise, more apathetic.”**

COVID-19 also had a detrimental impact on Laura's physical and mental health. As part of her treatment plan, Laura should have been having monthly blood tests and physical checks, however her GP had not maintained these. As a result of the lack of monitoring, Laura became seriously ill and was admitted to hospital. Overall, Laura's mental and physical health has become worse over the course of the pandemic:

> **" My health has become worse because I have had less of an incentive to keep myself well and it is easier to 'fall under the radar' as I haven't been having regular GP checks due to Covid."**

Laura finds it difficult to cope with change and likes to have a lot of structure to her days to be able to function optimally. It has been very difficult to live with the change and uncertainty that COVID-19 has brought. Although Laura has found it difficult to cope with the changing landscape, she has not wanted to access any additional support as she has lived with her conditions for so long, she already knows how best to manage them. Laura does not trust her employers as they are not very 'employee-centric,' and while she has not disclosed her long-term health conditions, she would not expect them to support employees on zero-hour contracts. Therefore, Laura has not received any adjustments or support from her employer:

> **" I try not to access support, nearly 55 and been through all the treatment… the way I found I like is to take my medication and just get on with my life."**

The subsequent lockdowns in November 2020 and January 2021 have been easier for Laura as she has been better able to maintain a routine. Because coffee shops have stayed open and supermarkets are better stocked, Laura is able to treat herself to her daily coffee and access the food she can eat. Small 'saving graces' like this make a huge difference to Laura's wellbeing.

Thinking about the impact of the pandemic overall, the substantial shift to the virtual world has left Laura feeling 'useless and helpless.' Laura cannot afford the newest technology and does not know how to use the plethora of online platforms that are required to stay 'up to date' in the current context. She feels as if 'society is running away' from her and that she is being 'left behind'. It is very easy to feel 'a bit thick' or 'left out' when you cannot engage with the technology. Laura feels that the government have a role to play in supporting the older generation with technological advances, especially those who are of lower income as it is 'not just kids stuck in the poverty trap'. Funded equipment and free lessons would help Laura to feel better part of society and less 'useless'.

The future

Thinking about the future is difficult for Laura, as she prefers to live day-by-day. Any thoughts beyond the immediate are 'too scary' and difficult for her to manage. Everyone has had to learn to adapt during the pandemic, and it is frightening to think about 'unadapting' when COVID-19 restrictions are relaxed:

> **"It scares me now because my life is about routine, the thought of having to adapt again is really really scary."**

During the pandemic, Laura feels that her generation had been forgotten about, as there is not that much funding and many helpful resources have now moved online.

> **"Provide us with the support and understand that our needs are different to the younger people… People who haven't adapted to technology we'll need to be acknowledged."**

As Laura finds it scary to go online, she would like to be sent more things by post, such as information on what is on offer for people of her age locally. She feels that the government and local authorities need to be more active in reaching out to people with long-term health conditions:

> **"When you're depressed you don't have the energy to seek things out, you need things to come to you."**

Karen – furloughed and living with a physical health condition

Background

Karen is in her sixties and has been working remotely in the property sector for the past three years. Her previous roles were in international development and involved international travel. In spring 2019, Karen was diagnosed with an aggressive form of cancer that had spread to other parts of her body. Over the course of eighteen months, she had to go through various forms of treatment, including five months of intravenous chemotherapy, surgery, radiotherapy, tablet-form chemotherapy, and bone-strengthening treatment. The effects of the treatment were completely debilitating, to the extent to which she could not brush her teeth or shower:

> **“The impact is beyond description, it’s like being on a different planet and it varies from day to day and depending on which treatment you are on.”**

For Karen, the cancer and the treatment impacted her life in three main ways: emotionally, physically, and by disrupting her relationships. Chemotherapy had a significant impact on her cognitive function, although this is a side effect not often talked about or understood by others. Following her chemotherapy, Karen found that her cognitive function appeared to ‘disappear altogether’. She would often find herself forgetting and having difficulties processing even short conversations, which would lead to her taking a long time to respond. As the cancer treatment significantly impacted her immunity, Karen was not able to maintain her social life over the period of treatment. She also developed a sense of guilt about the impact of her illness on those around her.

Physically, Karen lost her taste and smell, she was very sick and lost her hair. Although often considered a less significant side effect of the treatment, the impact of the hair loss was very emotional for Karen:

> **“Your hair shapes your identity. You look like a different person and people treat you differently. You have no idea how much you value your hair.”**

During and after the treatment, Karen was not able to ‘do very much of anything’. Initially, she thought she may be able to work while undertaking treatment, but she soon found out that this would not be possible due to the side-effects. Karen was signed off sick for most of the treatment, only occasionally attending meetings or training:

> **" It is very dramatic in all aspects, you lose your sense of self and where you fit."**

From a work perspective, she had initially intended for her current role to be a short-term position until she found something more aligned to her career history. However, as she was diagnosed shortly after starting the position, she was not able to search and apply for other jobs. Prior to COVID-19, the cancer meant that she could not do her work and could not attend meetings due to the cognitive impact of the treatment. While on sick leave, Karen has tried to stay in touch with colleagues on a social basis, and they have been incredibly understanding and supportive of her. Her employers have continued to pay her during this time, which has had a huge positive impact on Karen:

> **" The stress relief to still have the income all this time is beyond description. So, if that's all they do then that's absolutely amazing, considering I had worked for them for a year."**

Impact of COVID-19

When COVID-19 first struck, Karen initially did not think that it 'mattered' as she has been isolating anyway due to chemotherapy. However, it has had a 'huge impact' on her because it has made her more apprehensive and has stopped any social contact. At the point Karen finished her treatment and could have started going out and resuming normal life, COVID-19 hit. It has intensified everything for Karen; while she can still go out for a walk, she must go somewhere isolated because people do not adhere to the rules to protect themselves or others. Karen has not been able to have any visitors, which has been especially difficult because her daughter was an 'incredible support' during the first eight months of her treatment. As her partner is a key worker, they have been under a lot of pressure and working long hours, and therefore not able to fully support Karen.

> **" Covid made me anxious but not in the way you would expect. The big anxiety is other people's behaviours."**

Karen was on sick leave before lockdown began and then was placed on furlough, as were most of her colleagues. However, as she was already a remote worker, she was set up for working from home if it was needed. Her employer responded swiftly and provided everyone with the equipment they needed to work at home comfortably. They also provided mental health support for all staff in the form of a counselling offer, and while Karen did not take up the offer, as she was receiving counselling elsewhere, it was still appreciated. Although Karen has been able to attend training sessions while on furlough, she has found them difficult and has struggled to keep up. Being on furlough for the entirety of the pandemic has been both good and bad for Karen:

> **"In some ways it helps but in other ways it isolates you even more. What that does it leaves you in limbo. It's nice to be furloughed rather than be made redundant, but it's isolating. Without realising it, work is something of a support system."**

Due to the increased isolation, Karen lacks the external stimuli through sharing other's experiences, so everything must be self-generated, which can be very draining. The treatment that Karen receives has also been affected. Some of her doctors have not been able to treat her due to self-isolation and lockdown restrictions, and her GP has not been accessible or responsive. She is also required to attend all medical appointments alone, which is emotionally and practically difficult as it's only her there to take in the information, remember it and act on it. The government have appeared to take a blanket approach to those who needed treatment during the pandemic, but Karen thinks more consideration and adjustments were needed for those with long-term conditions, for example allowing a support person if the condition causes cognitive impairments.

While Karen feels more settled during the 2021 lockdown, she continues to be frustrated by people who disregard the rules. Living with cancer has made Karen realise that life is precious; she is angry at those who do not understand the impact of their actions and believe the Government need to stake a harder stance on those who break the rules:

> **"What makes me really angry is… this 'it won't happen to me so I can do what I want' attitude… you might be okay, but someone you come into contact with won't be. It's disgraceful and inconsiderate."**

Overall, the social isolation, the actions of others, and the lack of emotional and medical support has negatively impacted Karen's mental wellbeing:

> **"Covid has just made things so much more difficult for me personally; to deal with cancer, Covid has made it so much more difficult. Hospital appointments, getting hold of people. Cancer on its own would have been difficult enough, this has affected the work situation and it's effected my life, my treatment, everything."**

The future

Karen had hoped to go back to work in early October 2020. However, she had underestimated the continued impact of the treatment and was unable to return. She now hopes to return in Spring 2021. When thinking about her eventual return, Karen knows she will require a long-phased approach and will need ‘some time’ to get back up to speed. She thinks that she will probably work more slowly than she did previously, which may be problematic as her employer uses time tracking to monitor efficiency. Karen’s employer is very technologically advanced and has a young employee age profile, so she worries that it will take her some time to catch-up with all the changes that have taken place while she has been sick. Karen thinks that keeping up with technological changes is particularly difficult for older workers as they did not grow up as ‘digital natives.’

Karen hopes that her employers will understand and be mindful of the physical and emotional effects of her illness and adapt their expectations of her. As she is the first person to have experienced cancer in her workplace, she is fearful that her colleagues will not know what to expect or how to react. Karen feels that she is a different person now, not just in the way she looks but who she is, which has been hard to come to terms with:

> **“I don’t just look different, I am different. That’s really hard because I don’t always want to be different.”**

Karen has been working with the charity, Working with Cancer, to plan her transition back to work, they have helped her understand that she needs to drive the return to ensure she is fully supported. Some of her intended actions are organising a meeting with her employer to explain the challenges of readjusting; suggested a buddy system so she has someone she can talk to and support her; and sharing her health experiences with a wider group of staff to generate wider understanding. Karen is very comfortable driving the return-to-work process, as she is in control of the experience and is paving the way for future cultural and practice changes. She aims to introduce an approach that can be adopted organisational wide, rather than something specifically for her.

When thinking about the longer-term future, Karen is not sure when things will become ‘normal’ again for her as it all depends on the outcome of her treatment. The combination of COVID-19 and her health condition have made her ‘abandon’ her plans, as she cannot see how the situation ‘will play out’. Before her diagnosis, Karen had hoped to find a senior role in the sector she had worked in previously. However, due to the very generous financial support her employer has provided, she feels an obligation to remain with them. For now, she is going to focus on her current role and returning to work.

Emma – furloughed and living with a physical health condition

Background

Emma is 63 years old and lives alone in London. She has worked for an architect's practice for the past twenty-five years. In 2017, Emma was diagnosed with breast cancer and underwent surgery, chemotherapy, and radiotherapy. During this time, her employer was very supportive and continued to pay her full salary:

> **" They [employer] were fantastic. They said don't worry about your job or income, just concentrate on getting better."**

The cancer treatment itself was not 'too bad' as it was administered in three-week cycles and by the third week Emma felt well enough to go into work and touch base. To manage the condition in the long-term, she will take hormone medication and receive bone-strengthening treatment for the foreseeable future.

While Emma underwent scans for the cancer, she was also diagnosed with sarcoidosis of the lungs. She has recently started to worry about this more due to her limited knowledge of the condition; and while it is not currently being treated, she understands it can complicate other medical treatments. Emma tried to see a specialist to understand more, however waiting times were very long. Emma has also been diagnosed with osteoporosis, although this does not cause her any pain.

Emma **does not** feel that any of her health conditions impact her work, apart from requiring time off for appointments and treatment, so she did not need support or adjustments from her employer. While she does not experience any side effects or physical pain, the long-term conditions do cause 'a shadow of anxiety' to hang over her. However, she 'doesn't believe in expending worry energy needlessly."

Impact of COVID-19

Prior to the lockdown in March 2020, Emma's employer had begun to prepare for staff to work from home by setting up and testing the IT infrastructure. When the first lockdown was announced, her employer was prepared, and all staff began to work from home. New technology was introduced to help with communication and online lectures were set-up as social replacement for 'Friday drinks':

> **" I felt very lucky to work for such a responsible, efficient and caring organisation."**

Emma was grateful and relieved to be working from home as she was nervous about going out, particularly regarding her commute to work. Previously, she rarely worked from home, and even during her chemotherapy she only did it a small amount. Her employer conducted a DSE assessment at the beginning of the lockdown to ensure her working setup was safe. They supplied all the equipment she needed, including a keyboard to help with neck pain, and a chair because of her back ache.

Initially, Emma was advised by the government to shield, which meant her prescriptions were organised to be delivered and she could get priority delivery slots from the supermarkets as well as food boxes. This helped her self-isolation and reduced the burden financially. She also had a neighbour who would check if she needed anything about once a week. At the beginning of the pandemic, Emma experienced some delays to her monthly bone treatment, however, she did not want to have to travel into central London for it anyway, so this did not cause additional anxiety.

While working from home, Emma felt it was important to keep to a routine and therefore did not find she was working different hours. Being at home allowed her the flexibility to get some household chores done throughout the day. As a keen sculptor, Emma was using her art space as her workspace and she had initially put her sculpture away to make room, but she found that demotivating:

> **“I actually found that a bit sad. So having it [sculpture] out encourages me...at the end of work I can do the thing I really love.”**

After some time working at home, Emma’s employer asked her to go on furlough. As she was not a fee-earning employee, she understood why she had been chosen. Furlough was implemented in three-week periods, after which she would be contacted and told if she needed to return. Whilst on furlough, Emma was concerned about her finances as she was receiving about sixty per cent of her usual salary. She investigated doing some other work but did not go through with anything. Overall, Emma loved the time she spent on furlough. Her experience has made her look forward to her retirement even more.

> **“The weather was sunny so I was in my garden a lot and I set up an alfresco sculpture studio, so had a wonderful time doing the thing I love.”**

After nine weeks on furlough, Emma returned to working from home. Over time she grew accustomed to home-working and now actually prefers it. She has daily contact with her colleagues, both in meetings and for social catch ups, and values the extra time gained from stopping the commute to the office.

When the shielding advice ended Emma began to gradually go out again. She continued to avoid public transport, and instead used a hospital car to get to her appointments. She still gets her food delivered and cleans everything before she brings it into the house. She feels she had enough social support as she spoke with her family and friends on the phone and went for walks with friends.

Overall, Emma feels her mental and physical health improved over time mostly because the lack of commute gave her more time to exercise. She was also sleeping and eating better and maintaining a healthier weight. Emma has received the first of her COVID-19 vaccinations when she was attending her appointment for her bone treatment which she felt was very convenient.

Over time, the restrictions and lockdowns have, in some ways gotten easier for Emma as she has got used to the routine. In the beginning, she did not know anyone who had caught COVID-19, and she found it very alarming and was scared for loved ones' health. Whereas now she knows a lot of people who have had it, so she is more aware of it. She feels a greater sense of it 'closing in' as the reality of catching the virus gets closer to home, although she is confident she can avoid the risks if she continues to take precautions and stay at home. She has found that the news and social media can be depressing but also likes seeing the community coming together to respond when people need help:

> **" I think right at the very beginning when we were first aware of this thing going on…I did feel really quite alarmed…one really didn't know if loved ones were going to die or you yourself were going to get ill, whereas having got into the routine of taking all the precautions one can and knowing I'm not going to be expected to go into work or take any risks, at home I feel completely in control."**

The future

Emma does not foresee herself returning to working in the office five days a week. She would like to have a more blended work pattern but will still find it a challenge to go back to going into an office at all. She does worry that when she returns to working in an office, she will not be able to keep up with her exercise routine and may not stay as healthy.

In terms of her health conditions, she plans to follow the advice and treatment. She does find the sarcoidosis makes her anxious as she knows you can have no symptoms, but it can also be fatal, so she plans to speak to sarcoidosis support group about it.

The pandemic has caused Emma to think a lot about retirement, but she is working to pay off her mortgage first. Once she has paid it off, she may reduce her hours until she is of retirement age. Emma would like to be able to speak to her employer about her plans but is concerned about the consequences this might have. For a short period, she was anxious that the company would have to make redundancies, but ultimately, she feels mentally and emotionally ready to retire:

> **“ I would retire tomorrow if I could afford it…if they’d made me redundant I’d have punched the air because that would have made me able to afford it…I would have had to get some tax-free money from my pension but the value of having the time would have made me feel alright about that”**

She is a member of the Women Against State Pension Inequality organisation and feels strongly that older women have been treated unfairly by the changes in the state pension age. Personally, she ‘lost’ six years of her pension with no notice and believes the Government should lower the state pension age.

Emma has been surprised about how she has been able to adapt through the lockdowns and restrictions. She has always chosen to live alone but was initially worried how she would cope being on her own for weeks or months as she previously had a very active social life. However, she has learnt that she is able to adapt and can stay in touch with people even without seeing them.

Ben[5] – furloughed and living with a physical health condition

Background

Ben, 56, works in the building trade contracted by a large organisation. He was previously self-employed, but because of his health conditions he decided to opt for part-time contracted work. He was employed because of his expertise so that he could mentor an apprentice. Ben lives with Crohn's disease, and because of his health he sometimes cannot go out or be 'on-site', so some of his apprentice teaching is offered over video calls. On the occasions he cannot attend site, he can pass on the job to one of his colleagues:

> **"I help to mentor the apprentice. Because of my health, if I can't go out, they will call me by video-link, and show me the problem, and then once I can see what the issue is, I am them able to explain to them what to do."**

Ben has recently been diagnosed with Type 2 Diabetes. This results in a range of complications with regards to how to manage the two conditions, because with the Crohn's disease he can experience a lot of pain, which means he does not want to eat, but to maintain his blood sugar levels he must eat, which can then affect how his Crohn's reacts:

> **"It can be really hard to juggle. I can be in a lot of pain. I really would not wish this on my worst enemy."**

Living with Crohn's disease can be very difficult for Ben. As he now lives in a rural location with very few public toilets, he must be very cautious when going out. He has petitioned his local council about the issue, but nothing has been done to improve the situation. When he lived in London, because Crohn's is classified as a disability, he was given a key to use public facilities when needed. Managing Crohn's daily takes a lot of planning, and so when he knows he has a work appointment, Ben makes sure that he has enough time to prepare himself and to take his medication. This has been trial and error over the years, but he feels that this is more balanced now. He also must go to hospital every 6 weeks to have treatment to ensure that the Crohn's does not worsen.

Crohn's is a fluctuating condition, and can vary daily, which makes Ben very uncertain about whether he is going to be able to work the next day. When he is experiencing a flare-up in his condition it can be extremely painful, and he does

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[5] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries.

not want to interact with anyone. The pain during a flare makes it very difficult to focus on tasks and because of this he has been thinking about whether he can continue in his current employment. Having Crohn's also has an impact on Ben's mental health, as he described feeling 'miserable' and not able to recall having a 'good day' recently.

When he started his contract, Ben did disclose that he had Crohn's disease. His employer was very understanding as they had a family member who also lived with Crohn's. This 'lived experience' and knowledge of the symptoms meant that his employer could empathise with Ben and recognise the challenges this could have in an employment situation:

> **"I told my employer about my Crohn's, and his response was, I get it, I understand. Don't stress yourself about it."**

With regards to how much support an employer should or could give, having been self-employed, Ben recognised that it can be very difficult to provide adjustments when employers need to make a profit. He does have the option to refuse to take jobs if he cannot attend the site and use virtual methods for the mentoring. Ben mentioned that he had been 'laid-off' previously because of his Crohn's, and so the fact that his current employer is understanding and recognises the challenges of living with a chronic condition is support enough.

During the lockdown he was diagnosed with osteoarthritis, which adds further complications when continuing to work in a physical trade.

Impact of COVID-19

When COVID-19 cases were intensifying Ben became very stressed because he was classed as 'extremely vulnerable'. However, he received a letter recommending him to shield, which his employer understood and even sent two boxes of food to ensure that he had enough supplies. Ben was not happy about shielding as he was very bored and struggled to fill the time. However, when there was an emergency and there was really no-one available to help the apprentice, then he would volunteer to take video-calls to provide the advice and guidance. Ben also quite enjoyed doing it, as it kept his mind occupied and use the knowledge that he had:

> **"He couldn't really argue with it could he. It was an official letter from the government telling me to shield. And we both said that it would be really dumb to not follow the guidelines that are there to protect people like me."**

Ben was placed on furlough, which he appreciated as it still meant that he had 80% of his salary to help him financially throughout lockdown. His employer contacted him every so often during the lockdown to check in with him, to ask him about his health, and make sure that he did not need anything, which was really appreciated.

Even though lockdown made it easier for Ben to manage his Crohn's, in that he did not have to worry about planning his medication for trips out or worrying whether there was a public toilet in the vicinity, it did have an impact on his mental wellbeing. Even though in August, the shielding restrictions were amended, Ben was cautious about going out because of the risk of transmitting COVID-19, and the implications that this could have on his health:

> **"It was just really, really horrible not being able to go anywhere for over three months."**

The future

Ben is concerned about the impact that his health conditions will have in the future, especially for his employment. As a result of lockdown and the difficulty in getting medical appointments he has seen a deterioration in some of his symptoms, which adds to worries about how he will manage the pain from both his Crohn's and the osteoarthritis. Although Ben recognises that he still does have a lot of experience to provide, and knows that he is good at his job, the constant pain, and the impact this has on his concentration does make it difficult for him to work, and he does not see this improving in the future:

> **"I just can't see myself working in one to two years. The way I am feeling now, I don't want to kid myself into thinking that I still will be able to."**

Jonathan[6] – furloughed and living with a mental health condition

Background

Jonathan, 51, works for a large employer in the facilities department. He has been working with his current employer for around five years:

> **"It's not a desk job, the role involves a lot of moving around, sometimes a lot more than others, but it depends on what is happening during that day."**

For the last 12 years, Jonathan has lived with Obsessive Compulsive Disorder (OCD), and anxiety and depression (although this is more intermittent). His OCD manifests itself through over-cleaning, and over-checking in a variety of situations. This has had a major impact on how he has been able to live in his daily life. He describes constantly worrying about catching germs and illnesses from his surroundings and needs to clean himself, his clothes and whatever else he has come into contact in when he arrives home from work. This means that he has little time for relaxing in the evening. It also has had an impact on his social life, and where he decides to go out:

> **"It can have quite a debilitating effect on how I live my life…I spend more time trying to control my OCD than on other things that could be seen as more important. If I have been out, when I come in, it can take over 40 minutes to clean, when I know I can be doing something else."**

To try and manage the implications of his OCD on his daily life, Jonathan described trying to 'live with, rather than cure' it. He has previously tried counselling for his mental health (although this was predominantly for his anxiety and depression), but he finds it difficult seeking help. He now thinks therapy could be helpful as his mind is 'always on.' Jonathan does not ask anyone in his immediate work or home environment for support and does not like to talk about his OCD because he finds it very difficult and embarrassing as he feels there is still a lot of stigma around the condition. He admits to being too stubborn to ask for help sometimes, and feels that he has had the condition for so long that he is now unable to change his mind set:

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[6] This participant did not complete the second interview, so this case study is based on the first interview and any journal entries.

> **“ I have tried to seek some help, but it is quite an embarrassing condition to live with. It could be that I am too weak to change this at the moment…I just don’t think that it would help me, and that might just be me being stubborn or negative, but that is what I really think.”**

Jonathan started his current employment whilst living with his OCD, anxiety, and depression, and although his employer is not officially aware of his conditions, he suspects that they may have picked up on his behaviours at work. He attempts to conceal his OCD from his employer, and as a result has not asked for any workplace adjustments or other forms of support. However, he does employ several coping strategies at work; knowing his diary and the location of meetings help him mentally prepare for what this will involve and how to manage his behaviours in these settings. He also tries to pick work that involves minimal contact with people, which reduces the number of times he would have to wash his hands at work. Although he can ask his work colleagues for support on work-related tasks, he does not trust his colleagues to discuss his OCD with them and would not want to rely on them at work:

> **“ I really didn’t like shaking hands with people, sitting on chairs that I knew other people had sat on. I didn’t enjoy informal meetings where these scenarios could happen.”**

Impact of COVID-19

The enforced lockdown at the beginning of the COVID-19 pandemic had big implications on his mental wellbeing. Cleaning of clothes and surfaces became more frequent, and he was having difficulty in being able to relax and de-stress. He was finding work to be a negative experience, and although he was only supposed to work four days a week, increased sickness absence in the organisation led to him working more. This resulted in him feeling exhausted, not only due to the increased hours, but because his OCD and cleaning behaviours were draining. However, at the end of March he was then put on furlough for 4 months, as the organisation closed the office:

> **“ I was actually quite relieved when I was put on furlough, because before that I had been going in 5 days a week, and I was actually mentally exhausted.”**

Consequently, being put on furlough was a positive experience for him. He described not having to put himself in ‘danger’ anymore, as he did not have to go into work and move around the offices. He was relieved by this and it helped him control his OCD in some ways, as he was able to make choices about where he went and when. Jonathan was able to structure his day around tasks that he wanted to complete at home. He attempted to stay away from computers and negative news, as he had concerns about the transmission of COVID-19 and it spreading around his household. He described having to be cautious, although the 'hand, face, space' precautions, and cleaning shopping was not new to him, and in some way 'normalised' his behaviours:

> **"Not having to go into work was a relief, but there was still stuff playing on my mind, you know, all the stuff about the danger around Coronavirus was still there."**

Although his employers made the decision to put staff on furlough, and there was little consultation about the decision, Jonathan felt that was a fair decision because everyone was treated the same. With fewer people using the office, he understood that fewer facility staff would be needed throughout lockdown, and he though it better that staff were furloughed then having to make anyone redundant. Although this resulted in a 20% reduction in his pay, he was no longer having to commute, and had few concerns about his current financial wellbeing:

> **"Overall, I was happy with how they dealt with it."**

Jonathan was asked to return to work in August 2020 when some of the lockdown restrictions were lifted, however as there were fewer people in the office, he was more relaxed in comparison to how he felt pre-lockdown. He was also working fewer hours, which meant that when he did return form work, he would go through his cleaning routine, but still had time to relax afterwards.

To reduce the risk of transmission at work, some safety restrictions had been put in place, including one-way systems on stairwells, the availability of hand sanitiser, and limits to the number of people in the office to allow for social distancing. This meant that he had less contact with other employees, reducing the risks of any possible transmission, which he was pleased about. Seeing his employer had put workplace precautions in place re-assured him (as opposed to before the lockdown the situation was making him feel really stressed). However, part of Jonathan's work used to involve spending time outside of the office, but because of the pandemic there has been a slight change in his role, meaning those duties have now gone, and he is disappointed about that:

> **"Because of everything that has happened, right now there are less people in the office, so that helps me, because I don't have to confront as many people as I used to. It works much better for me in terms of my stress levels."**

During the earlier stages of lockdown, his manager made an effort to keep in touch with him, to check up in staff wellbeing and keep staff informed of any organisational and work changes. Management contact did reduce over time, and he was not sure why this occurred, but he would have appreciated more contact to settle anxieties he was having about work.

The future

When looking to the future Jonathan did not expect any changes with regards to his OCD behaviours. Although he had tried to make slight improvements, this did involve a lot of mental energy and capacity to undertake and maintain, and he questioned whether he had the strength to continue with this:

> **“I have really tried to streamline how I cope with my condition, I really have, but I don’t see it really changing any time soon.”**

He was adamant that work would return to normal when the restrictions were lifted, and nothing would change in terms of his work environment. Jonathan felt that he would still not disclose his OCD with his employer for fear of stigma and what may happen to his role.

Peter – furloughed and living with a mental health condition

Background

Peter is in his late fifties and teaches at a business school in central London. Before the pandemic, his role was permanent and full-time (including some additional evening work). Twenty years ago, Peter was diagnosed with bipolar disorder, although he believes that he had been living with the condition for most of his life, and so he described the diagnosis as a confirmation of what he believed he had been experiencing. For Peter, the severe periods of depression are the most debilitating part of his condition and occur more frequently than periods of elevated mood. As a result of several extended periods of sickness absence, Peter disclosed to his employer that he lived with a depressive 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.’**

When Peter experiences a severe depression, he cannot go to work, or have social interactions with anyone. It can last up to 1-2 weeks and occurs on average about 4 times a year. At the end of a depressive episode, he can feel anxious and exhausted as it is usually accompanied by insomnia, a side effect of the prescription medication that Peter takes. There is no indication when a depressive state will happen, and he has not recognised any triggers, so this can be difficult when it comes to work. Elevated moods occur less frequently (1-2 times a year) and last a few days; however, he believes that this does not affect his ability or performance at work, and continues to work during the elevated state:

> **“At the end of a depressive episode I do feel disinclined to go back to work, but I have to push through it. I worry these extended periods of sickness absence can put my job in jeopardy and the implications for my employment does nag at the back of my mind.”**

Both HR and his line manager know about his depression, and apart from allowing for extended periods of sickness absence when necessary, Peter does not feel that any further adjustments or support should be given, because in his opinion he is ‘there just to do a role and fulfil his responsibilities,’ and if he cannot do that, he should not have the job.

Peter also has chronic kidney disease, but he is not on any medication for it, and it does not affect his employment in any way. The kidney disease is monitored bi-annually at hospital check-ups and blood tests. However, if it does deteriorate this may lead to dialysis, but the disease has been stable for several years, so he is not worried about it.

Impact of COVID-19

As news of the COVID-19 pandemic arose, Peter developed anxiety and a fear of catching the virus. When the first lockdown was announced in March 2020, all staff at the business school were furloughed immediately, and his employer provided updates as and when necessary. It was originally thought that a return to work would occur in September, however, at this point furlough was continued. As a result of the subsequent lockdowns, Peter remains on furlough. There will be a review of the current situation at the end of the business school's 2021 Easter semester, and any return to work is contingent on the outcome of that review:

> **"I am still on furlough, with another review happening at the end of the semester. I would like to go back to work, to do face-to-face work."**

In October 2020, Peter started to provide online private tuition to students, which was beneficial if he was feeling depressed, and provides an added boost to his salary during the furlough period:

> **"I enjoy my job, but I don't altogether love it. The tuition is very much a means to an end and gives me the extra salary I need after being on furlough for so long."**

Peter has been given little information regarding what any return to work may look like, whether this will mean online or virtual teaching, or a return to the workplace. He commented that face-to-face teaching was preferable as it was more effective. He recognised that the business school were doing all they could in this difficult situation, but he would have welcomed some information about the potential viability of his role.

At the beginning of lockdown Peter experienced a depressive episode. He did not think that this was related to any anxiety that was caused by the pandemic, but it would have happened anyway. The episode lasted for two weeks, but this time he was comforted that he did not have to think about returning to work straight away or having to contact his line manager. It also meant that the side effects of the insomnia were more manageable, and he could adjust his days to a routine that suited him. Following the initial depressive episode, Peter believes that furlough has been beneficial for his health, as his mood has remained stable. He has enjoyed the extra time available for personal enjoyment. However, with the introduction of the January 2021 lockdown, his mood has changed, and it has been more difficult due to feeling lonely and socially isolated:

> **“I felt disappointed when lockdown started again in January and feel more affected by this one because of the seasonality. The inclement weather has meant it has been harder to go outside in comparison to the first lockdown”.**

Although Peter has felt medically well throughout lockdown, a routine blood test highlighted some anomalies which he fears may be associated to his kidney condition, and he is awaiting further consultations with his GP about this.

The future

At the beginning of the pandemic Peter was looking forward to a sense of normalisation and getting back to work. Although lockdown has been mostly beneficial for his mental health Peter does hope that his work schedule will return to pre-pandemic levels, although he has some concerns about his work and its stability because of the reliance on overseas students. If there continue to be restrictions on travel, he is unsure about the viability of his role.

> **“I am concerned about the stability of the role and enrolment figures, but there is no point in discussing these with my employer, as they have little control over the situation either, and unfortunately, it is just a fact of life at the moment.”**

Peter has not yet considered retirement, and the COVID-19 pandemic has not had any implications for retirement plans. His work provides him with a sense of purpose and social interactions with others which he has missed and enjoys:

> **“Retirement is in my sights, but I have no plans for it just yet. Covid has not changed this.”**

Peter voiced concerns about the possibility of redundancy, and he has some contingency plans if this is the case. He mentioned that he could continue with private tutoring and increase both the number of students and hours taught and look for other permanent jobs in the same field. He is however concerned that if he does have to apply for new roles that both his age and having a long-term health condition mean he could be subject to discrimination.

Julia – furloughed and living with a mental and physical health condition

Background

Julia is 53 years old and worked for two and a half years as a bar supervisor on a zero hours contract. Julia lives with several physical and mental health conditions. She was born with a genetic condition where she develops benign tumours on her body. The condition has become more apparent in the past 10 years and has started causing increasing problems; she frequently must travel to receive treatment from a specialist team. Some tumours can be pre-cancerous, so Julia has undergone many operations in the past. The tumours can also affect Julia's mental health when they are visible to other people because she is conscious of people looking at her. Julia also lives with nerve damage, which results in the inability to recognise pain, so her condition can have serious consequences. The pain is relieved with medication and rest, which can affect Julia's ability to work:

> **"Once I'm really in a lot of pain my body starts telling me, but it doesn't tell me before. So by the time I start taking pain meds I'm already in more pain than I should be, but my body is not registering pain until it is severe."**

Julia also has Emotionally Unstable Personality Disorder (EUPD), Obsessive Compulsive Disorder (OCD) and Post-Traumatic Stress Disorder (PTSD), which were diagnosed in 2014. The conditions can cause Julia to be outspoken and argumentative, and she describes it as 'seeing black and white,' and 'being unable to see the grey in the middle'. She also experiences intrusive thoughts, which are hard to control in stressful situations. To manage her mental health conditions, Julia tries to distance herself from situations that may prompt her to become argumentative. The intrusive thoughts are more difficult to manage as they can cause panic attacks. She uses coping mechanisms during these situations. Julia is on medication, although she does not find it effective, and she would like to try something different. In the past, she had psychological therapies to help manage her conditions.

Her physical health can impact her work as the physical elements of her job can be painful. She can draw on other colleagues for help, but this rarely happens. The role fits around Julia's health conditions because it is flexible and her employer is understanding, so she can take time off when needed. On several occasions, she has also had to go home because of the pain:

> **"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."**

Julia has not told her employer about her mental health conditions. However, she finds working is good for her mental health and she does not experience any intrusive thoughts when she is at work. Having space between her and the customers helps makes Julia feel relaxed and safe, and concentrating on something distracts her thoughts. Julia wishes she could work more but her physical condition prevents her. Working more than two days in a row can have severe consequences for her physical health.

Impact of COVID-19

Julia's workplace closed due to the COVID-19 restrictions and has not reopened. Initially Julia was put on the furlough scheme by her employer, however when the scheme changed, and employers had to contribute they no longer offered it. As Julia worked on a zero hours contract she was not expecting to be offered furlough, so did not mind when it stopped. Julia's employer has been good at communicating with staff and has set up a group on social media where colleagues can stay in touch.

Being out of work has been difficult for Julia as she has missed working and it has had an impact financially. To keep busy and give herself a feeling of purpose Julia started a project putting together gift bags to give to care workers. She also completed an IT course through People Plus as she felt it was important to use her time to learn new skills. Julia's mental health has also been affected as it has meant spending more time at home, which she finds challenging as working is an opportunity to have some time away from home and to socialise. She describes being at home during the lockdowns as like 'living groundhog day', however she values that she does not live alone, and recognises this would be much worse for her health:

> **"It [not working] hasn't affected me physically. Normally when I work it would be good for my mental health but my physical health would suffer because of the pain I'd be in the next day, so obviously that's not happened but it's affected me a lot mentally."**

Spending more time at home has made Julia feel claustrophobic and has intensified her intrusive thoughts. Sometimes her mental health impacts on her ability to carry out day-to-day tasks. Julia has struggled not being able to see her friends who would usually be a source of support, however using video calls has helped Julia feel less isolated:

> **"The restrictions in the past month have been difficult especially as it's been over Christmas and I think they will become stricter in the coming month. I feel my health is struggling a bit more both physically and mentally."**

Julia continues to manage her condition using medication and is waiting for a referral to a psychiatrist to get her medication changed. It is a long process; however this is normal and not because of COVID-19. One technique Julia has found useful to keep track of her health during COVID-19 is to write down her symptoms and track any patterns, and if she finds anything notable will contact her GP. During the lockdown, Julia needed to travel for additional treatment, but because hotels were not open, she had to check with the police to see if she could stay with a family member.

Since being out of work, Julia has applied for other jobs in retail and hospitality, however she has not been offered anything yet. She feels she is competing with 'thousands' of other people in the same situation. Her health limits the types of work she can apply for, but ideally, Julia would like a part-time job on a casual contract:

> **" 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."**

The Future

Julia hopes the restrictions will be lifted and her employer will reopen, however, she is not very hopeful. She worries about people not following the rules, and that people will not get the vaccine when it is offered, which will delay the ending of restrictions and when she can go back to work.

> **" I'm glad we are in a lockdown of some sort but plenty of people seem to be ignoring the rule[s] and doing what ever they want. I'm glad a vaccine has been rolled out but it will take some time to get to me. Hopefully the vaccine will allow people to start having a more normal life."**

Until she goes back to work Julia plans to continue to apply to jobs. She has thought about trying to find a more permanent role for one or two days a week. Julia does not feel able to commit to anything more because she does not want to let people down or worsen her condition. Julia is conscious of not working for the past year, as she thinks this will look bad to prospective employers. She is keen to continue to develop her skills and would like to start a course in a topic related to her interests.

Kate – not currently working and living with a mental health condition

Background

Kate, who is 62 years old, has worked part-time in a cafe for the past four years. Her role involved managing four or five other front of house staff, and she describes the job as busy and stressful. Since she was a teenager, Kate has lived with depression and anxiety. When she has a depressive episode, Kate will not want to leave her house and she will cancel her plans as they worsen her condition. Kate's health means she often feels unable to go to work and causes her to worry that she cannot do her job. On a bad day, Kate describes sweating, worrying about small things, having a short temper, and feeling nervous about her work. However, as Kate is part of a small team, she feels there is pressure for her to go to work because she does not want to let her boss down:

> **"I sort of overreact to having to do something…sometimes going to work is terrifying, because I know I've not only got to do my own job well but make sure everyone else does their job really well."**

To manage her condition, Kate has been on medication for the past year. Although she does not feel the positive effect of the medication anymore, she does not want to stop taking it in case that negatively impacts her mental health. Kate also tries to walk a lot and she has had therapy in the past. Kate feels that her employer is understanding of her condition, however she also recognises that if she is unable to do the job then her employer will have to hire someone else. There was nothing that Kate felt her employer could do to support her, although she did feel that her manager could more sincerely check on her wellbeing and provide reassurance that she is doing a good job:

> **"I'd like my boss to be more sympathetic to my mental health, but unfortunately I can't just cut off work if I feel stressed and overwhelmed… my boss needs me to be there to help run it…but I do get really nervous before every shift, it's a bit like being on stage working there…it's pressure."**

Impact of COVID-19

Kate has predominantly been out of work since the cafe closed during the first lockdown, apart from a few weeks in October 2020, when it was open for about a month. Kate's manager has kept in touch throughout the pandemic and has been up front about the situation, which Kate appreciates:

> **“I have returned to work with limited hours. This has affected my income badly and now it looks like the restaurant will have to close again. My future is a complete worry to me. I am suffering from insomnia because of all the worry.”**

Being out of work has severely decreased Kate’s confidence because of the amount of time she has spent alone at home. In the first lockdown, Kate decided to voluntarily shield because she feared getting COVID-19, and because there were a lot of elderly people who lived in her building and she was worried about infecting them. She is now part of a piece of research which means she gets tested for COVID-19 every week, so does not feel the need to shield. Not being able to see her family and friends has been particularly hard and she misses the support they give her. Although she is in a support bubble with her sister who lives locally, which helps. Kate experienced a depressive episode during the first lockdown but reported that she ‘managed to pull herself out of it’ by walking and engaging in self-care behaviours. She also started taking her neighbour’s dog for walks which is good for her mental health:

> **“I miss the company of other people very much and although I am able to see my sister once a week most weeks and a neighbour once a week, I’m still lonely.”**

The loss of work has given Kate severe anxiety, and she describes feeling very tense and being unable to relax. She is currently taking medication but does not feel it is working anymore so plans to speak to her GP. Kate also went through a period of engaging in destructive behaviours because of her anxiety, although this is getting better. Kate has been having some trouble sleeping and has started taking medication, but she recognises her sleep is better when she has done more in the day. She also went through a period of over-eating. Kate would appreciate having someone to talk to about her condition and how lockdown has affected her but knows that the NHS is overwhelmed at the moment so is hesitant to contact them:

> **“I went through a phase of comfort eating...and as a result put on half a stone in a short period of time! So, I’ve stopped doing that now and am trying to increase the amount I walk. I am depressed and anxious but am managing my condition okay. If I go out and have a decent walk daily I feel better generally and like myself more. If I have a bad day such as just sitting on the sofa comfort eating watching Netflix I hate myself and engage in self-destructive behaviours such as hair pulling.”**

The café closing made Kate anxious about the stability of her future employment. Being out of work has negatively affected Kates finances, causing her to worry more about money. Kate reported that her employer 'could not afford to put her on furlough', and she wishes the Government had provided some other financial support for people out of work such as herself. She is claiming Universal Credit which covers her bills, but she still must budget tightly.

Kate would value some employment support other than just financial support. She has been looking for jobs but does not expect there to be many vacancies as the hospitality sector remains shut. At this stage of her life, Kate is not prepared to start a new career, so she will wait and hope for her employer to reopen:

> **"There isn't an awful lot about, in my line of work in hospitality everything's shut and I'm not going to try and start a new career at the moment, I just have to wait, hopefully it won't be long now until it's open again."**

Kate is also concerned that the longer she is out of work, the harder it will be for her to return to work. She tends to 'hide away' because of her low self-esteem and being at home so much is re-enforcing those behaviours. Kate expects when she does return to work it will be difficult at first:

> **"The longer it goes on, the harder it's going to be for me to re-enter work and actually feel like I'm competent…it'll be really hard for the first few times or first couple of weeks, but then I'll just get back into the swing of it…I always think 'what was I worried about', I wouldn't be there if I wasn't good at the job, but trying to convince my head of that is a separate entity."**

The future

Kate hopes that she will be able to return to work and she may try and take on more hours. If it closes, she will have to look for another job elsewhere, but she worries that she will find it difficult to find work because of her age:

> **"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."**

In the future, Kate looks forward to being able to see her family again and having more of a routine as that is beneficial for her health. To manage her conditions, Kate plans to continue walking and engaging in self-care, and is also considering trying alternative meditation.

Kate believes the pandemic has highlighted what is important to her and helped her realise the value of having the basics in life. She is more grateful for the place she lives, being warm, and the food she eats, and feels she was ‘going overboard with materialistic products’ before. She also thinks this time has taught people the need to be kinder to others, and that if someone has plenty then they should give back.

Penny – not currently working and living with a physical and mental health condition

Background

Penny, 51, was working in three roles before the pandemic; her main income was from a zero-hour contract for an events company where she could work anywhere between ten and forty hours a week. In addition to this, Penny was a self-employed bookkeeper and offered entertainment services for the hospitality industry. Penny has several autoimmune conditions that cause her pain, excessive fatigue, and also affects her eyes, and skin. She also experiences anxiety because of her health conditions, which she takes medication to manage. She manages her conditions by staying healthy, exercising, meditating, and eating a good diet. She sometimes takes medication, but it varies depending on what part of the body the condition is having an impact on. Sometimes the medication can make her feel nauseous, so she tries to avoid it where possible.

She chose her job roles because of the flexibility they offer and the ability for her to work when she is feeling well. The zero hours role involves quite mundane tasks, which although take concentration, she can do without too much focus. If Penny were to work full time, she thinks it would have a detrimental impact on her health conditions:

> **“ 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.’**

In her day-to-day life Penny finds that her condition affects her memory, so she can forget words or how to do simple things like starting the car. The impact on her memory can make Penny feel ‘stupid’ and embarrassed. Particularly as in previous jobs she has experienced colleagues making fun of her. She has found that few employers understand the condition and the impact it has, although her current employer is understanding and patient:

> **“ It’s finding someone who understands that sometimes you can be a bit vague, it’s not that you’re actually stupid or you don’t understand it’s just that your brain’s not working quite in the way it should do…so to have a bit of patience…I find very few employers understand that hidden illnesses can be a bit odd”**

On a bad day, the fatigue can affect Penny’s day-to-day function, as she can struggle to complete household chores. When she becomes aware that she is finding things difficult it can exacerbate the fatigue as she tries to focus. On other days she might feel cognitively well but cannot physically function due to the pain. She finds this easier to deal with as she can more easily hide her pain from others.

Impact of COVID-19

Since COVID-19 and the restrictions, Penny has been out of work due to cancellation of events and hospitality closures. For her self-employed bookkeeping, over the course of the pandemic, some of her customers have slowly returned but she still is only working 2-3 hours a week:

> **" I have had a few customers return after leaving their accounts until the end of the year. It is good to feel useful again and everyone has been really good about safely giving me their documentation. I just wish I had more of it!'**

Being out of work has had a significant financial impact, especially as she fell through the gap of qualifying for any government support because of her employed status. She started looking for ways to save money and has had no disposable income to use for her enjoyment. She has applied for some additional jobs but has not heard anything back. Penny feels that there are few jobs being advertised but there is a lot of competition from younger and fitter people. Also, her health conditions limit the type of roles she can do, for example anything requiring some degree of physicality.

> **" Still no work and looking over the job sites every day relinquishes nothing suitable sadly. All very physical work or very long drives and very little part time."**

Penny thinks there needs to be more part-time and flexible working options to accommodate people's needs. She believes employers need to be encouraged to offer flexibility and for society to embrace more flexible ways of working. She also feels there is a lack of acknowledgment of the skills of people with long-term health conditions looking for part time work:

> **" 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"**

Generally, the pandemic has made Penny's conditions easier to manage because she has had more time to focus on her health. She thinks she is in better health now as she is not pushing herself as much, she finds she does not get as tired and is sleeping better:

> **“I’m feeling better because I’m not physically pushing myself...because I’ve had a lot of rest time, I’m getting more sleep, I’m getting more exercise...I’m not having to push and do extra hours and getting really really tired and getting ill.”**

Penny has found that walking, yoga, and meditation, staying away from stress and eating healthily has helped her conditions. However, her general discontent with the situation does reduces her energy levels, and the lack of things to do impacts her mental health. At the beginning of the pandemic, Penny tried to take up activities such as painting and volunteering. However, over time she feels she lost her sense of purpose, and the less she goes out, the more anxious she gets when she eventually does have to leave the house. For Penny, having less to do during the day heightens the impact of her condition:

> **“Stress and boredom is generally not great for the health and I have a lot of ‘can’t be bothered’ going on which means that I am not doing enough exercise and eating rubbish which I know makes me feel lethargic so it is a bit of a vicious circle!”**

Due to impact of COVID-19 on her mental health, in December Penny contacted her GP to get a higher dose of anxiety medication, but the appointment was cancelled, and she has unable to get another. Penny emphasised how difficult it is to get support for mental health in general. Her mental health was further impacted when her dad passed away. This made her more worried and stressed, and not being able to say goodbye impacted the whole family. Because of the social restrictions, and since her husband returned to work, Penny can feel quite lonely during the day. However, using technology to maintain social connections and to keep herself busy has been very beneficial for Penny:

> **“Health has been okay. Mental health less so. Lost my dad to Covid just before Christmas and that was hard. Not being able to hug and get together to share that loss takes its toll.”**

The future

Penny hopes when the hospitality sector opens her work will pick up again, however she is not sure if the events company will keep operating. If she does lose her job, she will have to keep applying for others, but she is not hopeful. She feels unsure of the types of jobs there will be after the pandemic, and if there will be a place for her. She is particularly worried about her age and the perception employers will have of her. For Penny, it would be useful if there was a job site that was specifically for the kinds of roles she is looking for: flexible, part-time work that is low stress but around other people:

> **“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.”**

Penny is not worried about the impact of returning to work on her physical health as she is more concerned about her mental health and thinks working and feeling useful is more important. She describes the working pattern she had before as a ‘lovely equilibrium’. This time out of work has made her realise how much she values working and she has been surprised how much she misses it and the basic human contact it gives you. She plans to continue with her hobbies as it helps her to concentrate better in general, which is beneficial for her work. She looks forward lockdown restricting easing and the thinks getting back to normality will help her improve her health.

As time has gone on, her sense of what the future holds has become more negative. Initially she thought the lockdown would end and things would go back to normal, but the additional lockdowns have made her more uncertain for the future:

> **“When the first lockdown happened there was this idea that you were going to come out of it and go back into normal life, and then gradually that didn’t happen and we went down into this lockdown again and it’s that ‘Is there an end?’ ‘Is there hope at the end of this?’…I think there is more of that uncertainty with this lockdown.”**

3. Discussion

This research tells the stories of twenty people aged 50 years and over who are living and working with a LTC during the COVID-19 pandemic. Although the experiences of the participants are unique to each person and vary widely across the sample, some commonalties can be observed. Amongst these commonalities, is an underlying resilience and determination within participants to adapt to the situation and find the positives where they can. Many participants demonstrate the ability to develop coping mechanisms to manage the impacts of the external context on their health, work, and personal lives. In this section the similarities and differences are discussed, considering how age and health has shaped participants' working and personal lives throughout the pandemic.

3.1 Impact of health on work before COVID-19

Participants were extremely diverse in the type and severity of the conditions they lived with, so the degree to which their health conditions impacted their work before COVID-19 varied. For some, the impact was minimal as their health was not perceived to affect their ability to find employment, attend work, or carry out their role. However, others reported more severe effects of their condition on their employment. Notably, the research found that:

- **Many participants felt limited in the jobs they could do and the hours they could work**, therefore they sought part time or zero-hour contracts. For some individuals, it was the direct effects of their condition that led them to engage in this type of work. In other cases, the decision to take up part-time or zero-hours work was based on their fears of how employers perceived their capabilities given their age or health condition. Additional caring responsibilities can also influence the working patterns that some individuals choose. For example, shift- or part-time work can enable individuals to meet their responsibilities at home. The COVID-19 context and increased caring requirements has amplified the need to have work which balances with home life.

- **Managing treatments and appointments can be as onerous as managing the LTC**. For those living with cancer, the treatment often had a bigger impact on someone's ability to work than the condition itself, specifically the effect on an individual's cognitive functioning.

- The **symptoms participants experienced often fluctuated day-to-day**, so many participants managed their work around the variations in their health. Those with mental health conditions were more likely to be unable to work when their symptoms were severe. However, this 'fluctuating' pattern is a feature of many of the conditions that become more common with age. This means employers need a change in mindset from seeing adjustments as a 'one-off' change, to a sustained framework of support.

- Participants also frequently reported living with numerous conditions; it was **particularly common for those with a long-term physical condition to have a co-morbid mental health condition**. Many participants had to balance the management of the symptoms of each of their conditions with work, whereby work may be positive for their mental health but have negative consequences for their physical health.

3.1.1 Disclosing a long-term health condition to an employer

Previous research has shown that disclosing a health condition can be particularly challenging for older workers, who worry about being 'written off' by their employers (The Centre for Ageing Better, 2018). However, **many participants in this study had disclosed their health condition to their employer**. This was more likely when participants were confident that their **employer would be supportive, and when they had a good relationship with their manager.** It was common for individuals to tell their employer because they required workplace adjustments, particularly for those with physical conditions. Some participants with mental health conditions felt it was important to discuss their condition with their employer to encourage a more open narrative about mental health in their workplace.

Several participants had not disclosed their health condition to their employer. Commonly this was because of the **perceived stigma related to their condition**, especially when there was a lack of wider understanding about the condition, or it was difficult to explain. **Non-disclosure because of stigma was more common amongst participants with a mental health condition**, particularly those with a condition that was more complex. There was a perception that employers understood anxiety and depression, but there was less understanding of other conditions such as OCD or bipolar disorder. Non-disclosure was also demonstrated by some participants with physical health conditions, especially conditions which were not visible. Greater awareness of invisible health conditions and their impact would enable those living with the conditions to feel more confident disclosing to their employer and allow employers to provide more informed support.

Participants also did **not disclose because they were still able to do their job well** and **did not want to be labelled as vulnerable**. These individuals did not want to be defined by their health condition**,** be perceived as needing to be looked after, or unable to do their job. Participants in this research did not recall age as a factor in their decision to not disclose- although previous research, as cited above, has found that this can be a factor. There was also evidence that participants did not disclose their condition because they **did not understand**

what their employer could do to help them. This may reflect a lack of awareness or understanding of their rights as an employee and the options that are available to support them.

3.2 Impact of COVID-19 on work

3.2.1 Working in the workplace

Evidence suggests that in June 2020, approximately 40 per cent of workers were required by their employer to attend their normal place of work in some capacity (CIPD, 2020). Only four participants in the sample attended their place of work at all during the COVID-19 pandemic. In general participants reported that their **employers had put new guidelines and procedures in place to ensure the workplace was safe**. Overall, participants were satisfied with their employers' response. Some of the guidance included wearing masks, social distancing measures, and additional cleaning regimes. There was **no evidence of employers routinely offering participants with LTCs any additional support or adjustments during the pandemic, such as increased flexibility, beyond the offer to the wider workforce.**

3.2.2 Working from home

The large-scale shift towards home-working in many occupations had the potential to bring substantial benefits to people dealing with some types of LTC. Evidence of some of those benefits included:

- Some participants enjoyed the **greater flexibility that home-working afforded** and felt that they could better manage their condition because of the extra time, for example from not having to commute. Participants reported taking more breaks, reorganising work tasks, or doing exercise during their lunch break.
- In cases where home-working brought bigger changes to job roles, some participants had **enjoyed learning new skills** and felt that some new ways of working were more efficient.
- Some participants reported **improvements to their health** as a result (see chapter 2.3).

However, participants also reported negative aspects of working from home, many of which were not related to their condition. These included:

- **Loss of social contact and increased isolation**. This was particularly pronounced for those who did not have family or other social support networks.

- **Blurred the lines between work and home life**. There was evidence that working from home had negatively impacted some participants work-life balance. Some participants reported working longer hours, in part due to an increase in workload (related to staff furlough and sickness) and occasionally due to feeling that they needed to prove they were not 'slacking' at home. This may relate to age and health condition, resulting in greater concerns about other people's perceptions of their work ability. Participants who had other responsibilities, such as caring, found it particularly difficult to balance the interaction between home and work life.

- Participants who had **started a new job during the pandemic** reported difficulties with virtual on-boarding and forming relationships with their new team. Virtual 'on-boarding' is important to help employees recruited during this time get to know their new team, organisational values, and role expectations. Having close and supportive mentoring and management at this time is critical to ensure individuals are settling into their new roles, that they know who to go to if they have questions or concerns, and that they feel like a valued and respected part of the team.

- Where participants saw substantial changes to their roles or ways of working, some felt **they had not been offered adequate training to be able to carry out their new tasks successfully**. Where participants experienced increased workloads or role changes, it does not appear that employers considered the impact of LTCs on their ability to meet the increased work demands.

The research also highlighted what employers could do to improve employees' experiences of home-working in relation to isolation and work capability:

- Participants felt that **clear and continuous communication from their employer** was key for maintaining a feeling of connectedness to the organisation and reassuring them about what was going on. At the beginning of the pandemic, it was particularly important for employers to be clear regarding their COVID-19 response, what was expected of employees, and changes to ways of working.

- Most participants were provided with virtual tools to communicate with colleagues such as video conferencing software, and there was some evidence of employers creating online events for socialising, such as virtual coffee mornings.

- **The line manager also played an important role in maintaining social communication**, with participants valuing regular check-ins that were not solely focused on work.

- Participants identified that it was important for **employers to understand and assess how any job design changes interact with their health condition** and provide the necessary support or adjustments.

Participants also reported methods they had instigated themselves to improve their experiences of working from home. They commonly recognised the **importance of maintaining structure and consistency to their day** and felt that having a routine helped them manage their health condition. For some people with mental health conditions, the loss of structure and the uncertainty caused by the COVID-19 restrictions had a significant detrimental effect. Individuals need to be supported to maintain a sense of consistency and normality when working from home, as it is very easy to slip into damaging behaviours.

3.2.3 Furloughed or out of work

Participants who were on furlough and those who were technically employed but out of work (eg, zero-hours contracts), were similarly affected by COVID-19. These findings echoed the findings of previous research with workers aged 50 and over who were furloughed at the start of the pandemic with or without a health condition (The Centre for Ageing Better, 2020b). The interviews showed:

- Not working led to many **participants recognising the value of work** beyond the financial necessity, as they described loss of purpose, social contact, and increased boredom they had experienced. Participants, regardless of age or health condition, were keen to return to work to fulfil their psychosocial needs.

- This group of participants commonly had **fears about their job security and ability to find another job**. Continuous extensions of the furlough period could increase anxiety if there was little communication from employers regarding what is occurring and what the implications of any changes were. Clear, up to date employee communication was important to reduce any anxiety regarding job stability. Fears were often exacerbated by perceived ageism in the labour market, as they would be competing with younger job seekers who would be more desirable for employers.

- **Financial security was also a large concern** for this group of participants. Some participants had missed out on the government's financial support due to their employment arrangement (eg, a combination of self-employment and zero-hours contracts). To alleviate some of the anxieties, clear and transparent employer communication about the situation was considered important. Many participants in this group **believed that their work would return when the pandemic ended** and so felt they needed to wait for this period to be over. However, as time had gone on, some **participants had begun to look for other work** for financial reasons, or in case their previous employment did not resume. This was more common as the pandemic progressed as participants perceived their current situation to be more long-term than they had done previously.

3.3 Impact of COVID-19 on health

3.3.1 Health management

A large amount of time and energy can be used when managing a LTC, because of both self-management activities and the negotiation of the health system. COVID-19 has made this more difficult for many of the participants.

In general, **most participants continued to manage their conditions with medication or treatment** as they had been doing before the pandemic. There was evidence of some disruptions to medical support because of COVID-19, such as delays to treatment, issues accessing medication, and difficulties getting appointments; in some cases, this led to serious medical consequences, such as hospitalisation. Many participants commented on the difficulty in accessing mental health support both before and during the pandemic.

Although some participants had positive experiences using remote consultations, **others were reluctant to contact their GP** because of the heightened pressures on the NHS, or because they were not confident a virtual appointment would be appropriate to assess their symptoms. When engaging in medical care, some participants reported having to make additional time or travel adjustments to be able to attend appointments. Moreover, they felt that **the blanket approach adopted by the government for accessing medical treatment (eg, attending appointments alone regardless of condition or medical needs) throughout the pandemic was not appropriate** as it did not consider individual health needs. For example, attending appointments alone when suffering cognitive impairments had significant negative consequences for individuals.

During the pandemic, and partly because of difficulties in accessing medical care, participants reported an **increase in the use of self-management techniques**, such as adopting healthier eating or exercise behaviours, to manage their conditions. Meditation was commonly used, particularly by those who had mental health conditions. Self-management during the pandemic was easier for participants because of the greater flexibility they had with their work. Employers will need to recognise that people may wish to continue more flexible ways of working because of the health benefits it has afforded them during this period.

The impact of health conditions on individuals' day-to-day lives can fluctuate, especially during periods of high stress. The pandemic alone has been a source of stress for many people. Other major life events continue to occur within this new context, which have caused previously very well-managed health conditions to worsen.

3.3.2 Changes to the impact of health on work

The research found that the pandemic altered the ways in which participants' health impacted their work – and not always positively.

- **Working from home or being out of work had led to improvements in some participants physical health**, as it provided increased time to manage their condition and requires less physical exertion than being in a workplace.

- A few participants reported that **new ways of working were now more difficult because of their health condition**, such as those with musculoskeletal conditions that make typing difficult.

- For those with co-morbid mental and physical conditions, **the shift to remote working practices has altered which condition is most impactful at work**. Before the pandemic, physical health was typically more problematic as it was exacerbated by attending a physical workplace. However, due to the restrictions and working from home, physical health often improved whereas mental health declined.

The isolation because of the restrictions had a major impact on many participants' mental health, which was exacerbated by working from home and having limited contact with colleagues. This was particularly true for participants who lived alone or had not been working at all or from home. While enforced isolation did help some participants feel more secure and protected from the virus, staying away from other people re-enforced negative patterns of behaviour that could perpetuate pre-existing mental health conditions.

3.3.3 Shielding

Several participants were instructed to shield by the Government, commonly those who had cancer. Overall, the **employer's response to shielding was supportive**, and participants were sent to work from home or put on furlough. Some other participants reported that **they were not asked to shield but did so voluntarily**. This was typically because they perceived themselves as vulnerable because of their health condition and were concerned about catching the virus.

The experience of **shielding was isolating for participants and affected some participants mental health because of the loss of social contact**. Some reported that it reminded them of their experiences whilst having treatment for their health condition, and that it felt like a step backwards in their recovery. It was reported that shielding was also boring and working from home provided them with a structure and something to do each day. However, it also contributed to a feeling or security and protection.

The **ending of the shielding advice was concerning for participants who had been following the guidance**, as they still felt vulnerable. Some participants decided to continue to take precautions, while others slowly started to go out again. Precautions included limiting social contact and travel, and additional cleaning regimes. Those who decided to continue taking precautions were typically working from home or not working, so their decision did not require any further adjustments from their employer. Employers can play a vital role in supporting this transition by considering return to work plans as restrictions ease.

3.4 Wider impact of COVID-19

3.4.1 Increased reliance on technology

The COVID-19 restrictions and move to increased remote working has **led to greater reliance on technology,** with both positive and negative effects.

Rapid introduction of new software and tools in many workplaces had been difficult for many participants because of the **assumption by employers that everyone would be able to continue to work effectively using the new technology**. This was a challenge especially where adequate training was not given to employees, particularly for those with a low level of digital literacy or cognitive impairment. While most older people are digitally literate, those who are not are more likely to be older (Centre for Ageing Better, 2020c). Participants felt that employers had overlooked the need to provide training to less technologically capable employees, typically those who were older. Concerns about re-enforcing negative perceptions about the digital literacy of older workers may have prevented participants from raising it as an issue with their employer.

Over time, some participants had grown to like the new technology. It was recognised that **use of technology could benefit an individuals' health**, particularly those with fatigue-related symptoms who now did not have to travel and had more flexibility in their work. **Technology could also be used to foster greater inclusivity** for those with health conditions and disabilities to attend events such as virtual training or conferences by removing physical barriers.

3.4.2 Finding work

Participants discussed **concerns about their ability to find work.** There was a common perception that the **labour market was competitive**, particularly in certain sectors such as hospitality, where there were a lot of other people also looking for work. Age was reflected in participants' concerns as they reported previously **experiencing ageism in recruitment, and felt they were unable to contend with younger people** in the job market.

Living with a LTC also made people feel that the roles for which they could apply were limited, commonly because of the physical impact of their condition. Many participants also described a **need for great flexibility in their work to fit with their fluctuating health needs**. Participants often wanted part-time or flexible work, and there was some lack of awareness of where to find these roles.

For some people, the long periods of being out of work through the pandemic have offered an opportunity to develop new skills. To support people back into the labour market, it will be important for people to be able to demonstrate how the new skills they have learnt can be transferred to the workplace.

3.4.3 Value of work

Many participants reflected on the **value that work provides them and how it fulfils their psychosocial needs**. Working provided participants with a sense of purpose and meaning. Some participants also found work to be a distraction from their health condition as it gave them something else to focus on. It was also clear, especially during the pandemic, that participants valued the social aspects of going to work and being around other people.

While earning an income was the primary motivator to work for some participants, others were fortunate to be able to choose to work for other reasons. The pandemic provided an opportunity for **older workers to think about the use of their time and what they value going forward**.

3.5 Sources and type of support

The research showed that participants sought support from work and non-work sources. Both of these were valuable in supporting participants to manage their health and work before and during the pandemic.

3.5.1 Non-employer sources of support

Both before and during the pandemic, the **support received from family and friends was most valued** by participants. These networks provided social, emotional, and practical support. During the pandemic, participants often relied on family and neighbours for practical things such as shopping, while family inside the home could provide the social and emotional help. Some participants were also in **contact with charities or local services**. For those who used these services, they were a useful external source of support to help understand their condition, their employment rights, and what their condition means for their future.

3.5.2 Employer support

Practical support was most frequently provided by employers both before and during the pandemic. There were fewer examples of employers providing financial or emotional support.

Before the pandemic, employers conducted Display Screen Equipment (DSE) assessments for all staff, and **often provided specialist equipment** such as a chair, mouse, keyboard, or desk, when identified as a required adjustment. There was also some evidence of referrals to occupational health, who commonly assisted with making workplace adjustments or with return-to-work plans. Support from occupational health helped participants get the equipment they needed or adjust after a return to work and continue their work effectively. Participants highlighted that if any changes were implemented it was important that they were regularly assessed and adapted if necessary. **There was some evidence that adjustments made for participants before COVID-19 were removed or stopping during the pandemic**, such as allotted medical breaks or extra supervision. During the pandemic and because of the shift to home-working, **the majority of employers conducted a further (DSE) assessment** for those working at home. Where identified, additional equipment was provided, although again this was implemented for all staff, not just those with LTCs.

Participants also commonly reported that before and during the pandemic their **employer offered flexibility or time-off such as to attend health-related appointments**. **Flexibility in working patterns or how they managed their workload was also offered**. Participants described having autonomy over their hours if they met their deadlines, which enabled them to better manage their condition. Greater flexibility was even more common during the pandemic as more people had been working from home. A few participants also **received financial support from their employer** such as a generous sick pay entitlement, which alleviated anxieties during sick leave.

Some of the most **valued, but lacking, support was the socio-emotional support provided by line managers**. Not all participants experienced this type of support as it appeared to be dependent on the quality of the line manager and the line management relationship. Participants who did not receive regular communication from their line manager typically cited this as the support they would have most valued during the pandemic. Employees with LTCs valued non-judgemental attitudes when discussing their health condition and simple reassurance that their employer understood their condition and will support them. Regular check-ins also provide the opportunity to identify and deal with any issues before they escalate.

It is important, however, that this communication does not focus only on work and it is also an opportunity to discuss personal matters. While lived experience of a condition may help line managers understand and empathise, they should be aware of the boundaries between a professional and personal relationship. Striking the balance between work and personal communication provided individuals with the opportunity to discuss the impact of their LTC.

Before and during the pandemic, there **was very limited evidence of employers providing specialist provisions or preventative action** for those with LTCs, with their needs typically being assessed on an ad-hoc basis after the individual raises a problem.

3.5.3 Better employer support required for those with LTCs during and beyond COVID-19

There were several ways that participants identified their employer could better support them within the COVID-19 context and in the future. Many participants **desired greater emotional support from their employer** and described a need for more of the 'soft stuff', in addition to practical workplace adjustments. This support most often comes from a line manager, and so employers need to supply their managing staff with effective training which enables them to support someone with a health condition.

It was **important for individuals to play an active role in identifying the support they needed**. Following a diagnosis, individuals did not always need to stop working altogether, but it was important that **job design was considered** to see what changes could be made to meet their needs. Needs are likely to change over time, so job design should be regularly reviewed, and employers must acknowledge that capability is likely to change and fluctuate long after a diagnosis and treatment. For many participants, **flexible, part-time, or home-working** offered the support to enable them to continue working. It was felt that there was increasingly greater acceptance of these ways of working by society, particularly after the large-scale home-working that has taken place as a result of COVID-19. Participants wanted more employers to be encouraged to offer these ways of working in the future.

Participants also wanted their **employer to have greater awareness and understanding of their condition, the impact, and how their symptoms may fluctuate**. In some cases, participants felt that their manager's lived experience aided their understanding of the participant's condition. However, it was also reported that bringing one's pre-conceived ideas about a health condition can be detrimental to the provision of support. Employers need to focus on understanding the individual's experience of their condition. Better understanding of the individual's lived experience can help employers provide more adequate support.

Employers' support also needs to be long-term, and continuous. For example, some participants emphasised that employers need to not assume someone is recovered after receiving successful treatment. Some participants felt that a lack of understanding of their condition led people to think they were 'better' because they had had a good day where their symptoms were not as severe, but it just represented the fluctuating nature of their condition.

3.6 The future

In general, participants found it difficult to think about the future. Some participants were avoiding making long-term plans because of the uncertainty of the current context. Of those who did discuss the future, there were common themes regarding the COVID-19 context, returning to work, and reflection and reappraisal of their future plans.

3.6.1 The ongoing impact of COVID-19

As the pandemic progressed, there was a **greater acceptance of the ongoing implications of COVID-19**. Participants grew accustomed to taking precautions and following the Government guidelines. There was also less fear about catching the virus as time passed, and more concern about how long restrictions would be in place and the impact it would have on their health and work. Over time, **participants grew frustrated at other people's behaviour and rule breaking** as this posed them a greater risk due to their age and LTCs. Likewise, many participants had **concerns about vaccine take-up** and the impacts that could have on their health. There was also more frustration with the Government's response and support, particularly for those who felt they had not received adequate support.

Participants also discussed the **challenge of transitioning back to the 'real world'** following the pandemic. This was especially worrying for participants who had been shielding or very isolated. As the restrictions are phased out, some participants felt they would be more vulnerable to catching the virus. A few participants reported that they would continue with some of the precautions they had adopted such as social distancing and additional cleaning routines, to stop them getting other illnesses in the future.

3.6.2 Returning to work

Some participants considered how they would like to work following the pandemic. **There was variation in the degree of home, office, or combination working participants desired in the future**. This mainly depended on how negatively not attending a workplace had impacted them during lockdown and what they wanted to prioritise going forward, particularly for those with co-morbid mental and physical health conditions. For many participants, the negative effect of not attending a workplace on their mental health, outweighed the positive gains that it had for their physical health. This led them to want to return to a workplace, even if it was detrimental physically.

Some participants also discussed the **use of the technology** and new tools their employer had introduced. Where virtual methods had helped their health, participants hoped that they would be able to continue to utilise these new ways of working and continue to develop their technological skills.

3.6.3 Reappraisal and reflection

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 had 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 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 had not explicitly changed 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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Let’s make ageing better.

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The Centre for Ageing Better creates change in policy and practice informed by evidence and works with partners across England to improve employment, housing, health and communities. Ageing Better is a charitable foundation, funded by The National Lottery Community Fund.

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